

**BREAKING
DOWN BARRIERS,
BREAKING THE SILENCE:**
MAKING HEALTH CARE
ACCESSIBLE FOR
WOMEN WITH
DISABILITIES

Report Co-Authors

Independence Care System

Independence Care System is dedicated to supporting adults with physical disabilities and chronic conditions to live at home and participate fully in community life. ICS operates a nonprofit Medicaid managed long-term care plan (MLTC) serving residents of Manhattan, Brooklyn, the Bronx and Queens. Member-centered care coordination is the heart of our work, aimed at ensuring that our members' needs are comprehensively assessed, that they participate in developing their Care Plans, and that they are followed during transitions from a hospitalization or nursing facility back home. Using an interdisciplinary team model of care management, our Care System is responsive, coordinated, expert, empowering, respectful and flexible.

Founded in 2000, ICS was the only plan in New York focused on the unique needs of people with physical disabilities. Since then, our membership has grown to more than 3,000—both people with disabilities and senior adults. We operate a nationally recognized Disability Care Coordination Model and award-winning specialized care management programs in Multiple Sclerosis, Women's Health, and Wheelchair Evaluation and Support.

New York Lawyers for the Public Interest

NYLPI is a nonprofit civil rights law firm whose mission is to advance equality and civil rights, with a focus on health justice, disability justice and environmental justice, through the power of community lawyering and partnerships with the private bar. Created in 1976 to address previously unmet legal needs, NYLPI combines a pro bono clearinghouse with an in-house practice that blends innovative lawyering, community organizing and advocacy.

NYLPI employs a community lawyering approach that revolves around the concept that change is best affected through a dedicated and organized local constituency responding to self-identified problems within their community. In order to address these concerns, NYLPI combines strategies such as advocacy, outreach, organizing, community education, capacity building, policy work, media, and litigation. NYLPI's close working relationship with our almost 100 member firms enables us to leverage the tremendous resources of the private bar in order to have the most impact on the lives of both our clients and New York's nonprofit community.

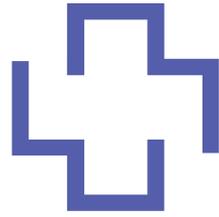
NYLPI's Disability Justice Program has created a special project, Access to Health Care for People with Disabilities, to break down the barriers that New Yorkers with disabilities face when seeking accessible health care. 



25 Elm Place, 5th Floor
Brooklyn, New York 11201
www.ics.org



151 West 30th St., 11th Floor
New York, New York 10001
www.nylpi.org



**BREAKING
DOWN BARRIERS,
BREAKING THE SILENCE:**
MAKING HEALTH CARE
ACCESSIBLE FOR
WOMEN WITH
DISABILITIES

October 2012

“There are too many women with disabilities who have been silenced. We can’t be. Some people don’t want to tell their stories because it’s so painful. When it comes to health care, it’s happened so many times, it feels like it’s not going to change.”

—M. Lyons, Member, Independence Care System

Acknowledgements

Breaking Down Barriers, Breaking the Silence: Making Health Care Accessible for Women with Disabilities was written by Kelly McAnnany, Katherine Terenzi, and Mindy Friedman from New York Lawyers for the Public Interest and Marilyn E. Saviola from Independence Care System.

The authors acknowledge the invaluable contributions to this report provided by New York Lawyers for the Public Interest staff and interns, including Aditi Shah, Kate Richardson, and Elena Zoniadis.

The authors gratefully acknowledge the amazing staff at Independence Care System for their tireless work on behalf of people with disabilities, including Rick Surpin, Regina Estela, Loreen Loonie, Angela Bonavoglia, Susan Wolf, Anna Martinez, Carole Baraldi, Jane Dillera Nietes, and Catherine V. Crowther.

Independence Care System and New York Lawyers for the Public Interest are deeply grateful to the women who courageously spoke out against injustice by sharing their stories in this report. We also recognize all of the participants in Independence Care System's Women's Health Access Program, whose important contributions have helped advance the struggle for accessible health care in New York City.

Table of Contents

Preface - 1

Executive Summary & Recommendations - 2

Common Barriers to Accessing Health Care Services - 5

Legal Framework for Providing Accessible Care - 8

The Costs of Inaccessible Health Care - 10

Case Study: Accessible Cancer Screening Services
for Women with Disabilities - 13

Next Steps for Accessibility Across New York City - 17

Recommendations to Providers & Policymakers - 18

“When we talk about concerns with disparities in access to health care, we don’t usually hear people with disabilities mentioned. There are a few reasons for this silence.

The Disability Rights Movement has long fought against society’s tendency to label people with disabilities as “sick” and dependent on doctors. During the early days of the Independent Living Movement, in an effort to distance itself from this ‘medical model’ of disability, advocates focused their energies on other areas, such as transportation, education, and employment. In addition, individuals with disabilities have not as easily spoken out or attempted to break down these barriers because they don’t realize accessible health care is a right. Many individuals with disabilities are just grateful for any care they can get — they don’t want to risk losing it and think that speaking up will get them in trouble. People with disabilities don’t always understand this is not the best they can get, and that they deserve more. As a result, hospitals, doctor’s’ offices and clinics have remained inaccessible to people with disabilities.

Everyone benefits from accessible care and universal design. At some point in your life, you’ll probably need something accessible. When you have an adjustable table with varying heights, pregnant women and the elderly don’t have to climb up and it’s more comfortable for all patients. It’s also easier and safer for the practitioner to provide care. Doctors don’t have to worry about hurting themselves or the patient.

It is late in the health care game to finally address this crucial issue, but the health of people with disabilities has suffered for far too long. It’s time to make health care accessible throughout New York City.”

**—Marilyn E. Saviola, Vice President of Advocacy and
the Women’s Health Access Program,
Independence Care System**

“The law is clear — medical providers of all sizes across New York City are obligated to provide equal care to their patients with disabilities. Yet, our office has heard from many New Yorkers about unequal access, whether because of provider bias, communication barriers, or equipment inaccessibility. This discrimination has prevented people with disabilities from equally availing themselves of critical health services, which we know leads to health disparities. New Yorkers with disabilities cannot be made to endure this injustice any longer.

We will fight alongside the disability community to ensure that medical facilities come into compliance with the law. Healthcare providers in New York City would be well served by taking immediate steps to make their services accessible.”

**— Kelly McAnnany, Co-Director, Disability Justice Program,
and Katherine Terenzi, Taconic Policy Fellow
New York Lawyers for the Public Interest**

Preface

Independence Care System (ICS) and New York Lawyers for the Public Interest (NYLPI) have long heard complaints from individuals with all types of disabilities about the pervasive inaccessibility of health care in New York City (NYC). These barriers exist in facilities of all sizes, including hospitals, community clinics, and doctors' offices, in contravention of laws that mandate equal access for people with disabilities. ICS and NYLPI have partnered to write this report to illuminate these barriers and to call on medical facilities and state and local government to take immediate action to stop this rampant discrimination. The time for accessible healthcare in New York City for people with disabilities is long overdue.

Inaccessibility is the result of architectural and communication barriers, inaccessible equipment, and provider bias, and the resulting disparities are well documented. Studies have shown that individuals with disabilities are far less likely to access health care services than individuals without disabilities.¹ Women with disabilities, in particular, are significantly less likely to seek or receive quality health care in a timely way, especially in the area of cancer screening.² Such significant lack of access to critical services leads to poorer health outcomes for women with disabilities, including higher mortality rates.³

The need for accessible care will only increase in the coming years as the baby boom generation ages and life expectancy rates lengthen. Nationally, if the prevalence of major chronic conditions remains the same, the number of individuals with functional limitations will have increased by over 300% by 2049.⁴ In New York City, where elderly residents are far more likely to have disabilities,⁵ the population over the age of 65 is projected to increase by 44% – or more than an additional 400,000 people – by the year 2030.⁶

Other demographic trends in New York are significant: New Yorkers with disabilities are more likely to be women;⁷ over 675,000 adult New Yorkers with disabilities are uninsured or publically insured;⁸ and nearly a quarter million adults with disabilities living in New York City earn an annual income that falls below the poverty line,⁹ with over half making less than \$25,000 in the last year.¹⁰ Despite the obligation of all New York City hospitals to ensure accessibility for their patients, Health and Hospitals Corporation (HHC) facilities have an especially critical role to play in supporting the large number of individuals with disabilities living in poverty¹¹ who disproportionately rely on the public health system.¹²

With the help of ICS, a few NYC health care facilities, including HHC facilities, have begun to make accessibility improvements for women with disabilities who seek a full range of health services, including breast and cervical cancer screening. These improvements did not generate great expense. Yet, they produced life-changing results for the women who finally benefitted from fully accessible care. These small instances of increased accessibility demand replication, as all New Yorkers with disabilities are entitled to accessible health care.

Medical providers and policymakers have an important role to play in bridging this gap to accessible health care for people with disabilities. This report will provide an overview of the barriers to medical care encountered by New Yorkers with all types of disabilities, as well as outline the legal framework that protects their rights. This report also includes a discussion of the various benefits reaped by medical providers who deliver accessible health care. This report will subsequently probe the specific case of barriers to cancer screening for women with physical disabilities, including the successful steps taken by some New York City providers to be disability inclusive. Finally, this report will make recommendations to medical providers and policymakers on how to fundamentally improve access to health care for New Yorkers with disabilities.

I try to think about it from the perspective of the doctor. I want to believe that they want to give us the best health care, but sometimes the doctor doesn't think about whether the space is accessible, because they're so busy thinking about the services they're supposed to be providing. I wish they'd think about both.

– M. Lyons, Member,
Independence Care System

Executive Summary & Recommendations

Executive Summary

Over the years, Independence Care System (ICS) and New York Lawyers for the Public Interest (NYLPI) have heard numerous complaints from individuals with all types of disabilities about the inaccessibility of health care in New York City. Barriers to comprehensive, quality health care appear in facilities of all sizes, including hospitals, community clinics, and doctors' offices. Inaccessibility is the result of architectural and communication barriers, inaccessible equipment, and provider bias. The effect of these obstacles to care is profound; inaccessible health care negatively impacts nearly every aspect of an individual's life, including their social, psychological, physical, and economic well-being. Disparities in access to medical treatment for individuals with disabilities are well documented. Studies have shown that people with disabilities are far less likely to access health care services than individuals without disabilities. Women with disabilities, in particular, are significantly less likely to seek and/or receive quality health care in a timely way, especially in the area of cancer screening. Such significant lack of access to critical services leads to poorer health outcomes for women with disabilities, including higher mortality rates.

Federal, state, and local laws prohibit both public and private health care facilities from discriminating against individuals with disabilities in the provision of medical care. In fact, New York City's local human rights law is one of the most progressive in the country and offers protections beyond the federal laws. Generally, this means that medical providers are responsible for ensuring the accessibility of programs and services by removing architectural and communication barriers, providing reasonable accommodations and accessible medical equipment, training medical and non-medical staff, and making changes to institutional policies and procedures. Compliance with disability anti-discrimination laws benefits patients and providers alike. Not only does the provision of accessible health care ensure a safe environment for patients and employees, but it also reduces the costs associated with patient lawsuits and lost time and expense for worker injuries. Further, medical providers can take advantage of tax incentives for making services and facilities accessible to people with disabilities. Finally, the costs to the health care system are reduced when patients can access care equally, as diseases and illnesses are prevented or diagnosed earlier, and treated for less money, and patients are not forced to rely inappropriately on emergency department treatment.

“My mother and my father both died from cancer, two of my aunts had breast cancer, my brother has cancer, and my sister has breast cancer. Cancer runs in my family so I need to get screened. When I went to one private hospital to get a mammogram the machine didn't lower. During the test my legs started shaking and I felt like I was going to fall and hurt myself. So, I told the woman that I need to sit. She was so rude, she said I could sit when we were done.”

– Azzlee Blackwood, Member,
Independence Care System

Barriers to health care disproportionately affect women, and can produce particularly harmful results when they impede effective screening for cancer; disparate treatment can delay or inhibit the early detection of breast or cervical cancers. Although women with disabilities have the same incidence rates of breast cancer as women without disabilities, they are one-third more likely to die from it. Women without disabilities also receive mammograms eleven percent more frequently than women with physical disabilities. Studies have shown that among women with disabilities aged forty and over who had not had a mammogram within the past two years, the most frequently cited reason was the inability to get into the required position.

Although the majority of medical facilities have a long way to go to come into compliance with disability laws, efforts to achieve accessible care are

already underway in New York City hospitals. ICS, which operates a nonprofit Medicaid managed long-term care plan specifically designed for adults with physical disabilities and chronic illnesses, has spent several years developing its Women’s Health Access Program. This program seeks to increase the accessibility of breast and gynecological care and other health services for women with physical disabilities. ICS, along with partner medical facilities, has made significant progress in developing and implementing a model of accessible cancer screening for ICS members. The key to this program’s success has been a willingness by providers to take necessary steps to change policies and procedures, remove physical barriers, and educate staff to ensure disability competency. The success of these collaborations must be replicated across other healthcare facilities in New York City.

“Women’s health care is important, and it is even more important for women who use wheelchairs. People don’t realize that when you take away the wheel chair, I’m just a woman looking for health care.”

– C. Cruz, Member,
Independence Care System

The time for accessible health care has come. New York City medical providers must immediately take steps to remedy the pervasive inequality that leads to substandard health care for New Yorkers with disabilities.

Recommendations to Medical Providers & Policymakers

Medical providers and policymakers have important roles to play in bridging the gap to accessible health care for women with disabilities. The following recommendations, if implemented, will make long overdue changes to our health care system and help guarantee equal access to health care for people with disabilities in New York City.

New York City Medical Providers should:

- Develop and implement a comprehensive plan for treating people with disabilities, including by instituting a non-discrimination policy with accompanying protocols, designating a point person and creating a grievance procedure to ensure patients with disabilities receive disability accommodations
- Develop and conduct mandatory system-wide disability competency provider trainings
- Acquire accessible equipment and remove communication and architectural barriers
- Coordinate care and maintain good data and records on patients with disabilities

The New York City Health & Hospitals Corporation should, in addition to the aforementioned recommendations:

- Convene a task force, including representatives from each facility, experts, stakeholders, and people with disabilities, to develop detailed guidance on ensuring accessibility in health care facilities in compliance with existing law
- Develop and disseminate a patient and provider survey regarding the accessibility of HHC facilities and services

The New York City Council should:

- Pass a comprehensive resolution, which directs New York City medical providers to comply with disability anti-discrimination laws; directs HHC to convene a task force to develop guidance on accessibility; urges the New York State Department of Health to issue and enforce detailed guidance to health care facilities on the provision of accessible care, to create an accessible complaint process, and to amend facility requirements to include disability training and intake; and urges the New York State legislature to pass legislation requiring medical facilities to procure accessible medical equipment and to issue patient notices regarding their right to accessible care
- Include funding in the budget, with terms and conditions, to assist capital improvements at HHC facilities that are designed to increase accessibility for people with disabilities
- Convene annual oversight hearings on the accessibility of medical services and the needs of people with disabilities

The New York State Department of Health should:

- Issue a detailed administrative directive to all medical facilities regarding the obligation to provide accessible services to people with disabilities, and ensure facility compliance with said directive and disability anti-discrimination laws
- Create a robust and accessible complaint process with defined follow-up procedures
- Amend facility requirements on training and intake to include disability

The New York State Legislature should:

- Pass legislation requiring all medical facilities to provide notice to patients of their rights to accessible care
- Pass legislation requiring all medical equipment procured by hospitals and clinics to be accessible in compliance with anti-discrimination laws and regulations

“Our sexual health is extremely important. We are the ones bringing life into this world. Yes, disabled women are also bringing life into this world. It is extremely important.”

– Kim Yancy, Member, Independence Care System

Common Barriers to Accessing Healthcare Services

“A physician shall support access to medical care for all people.”

– Principle IX,
American Medical
Association’s Code
of Medical Ethics ¹³

**“One public hospital mammo-
graphy supervisor even told me,
‘People like you cannot come here.’
When I asked where I should go,
the supervisor responded ‘where
people like you go.’”**

– Marilyn E. Saviola, Vice President of Advocacy and
the Women’s Health Access Program,
Independence Care System

New Yorkers with all types of disabilities face barriers to accessing basic health services, whether at hospital-based facilities, community clinics, or doctors’ offices. Obstacles include structural barriers, inaccessible equipment, communication barriers, and provider bias. The effect of these obstacles is profound; inaccessible health care negatively impacts nearly every aspect of an individual’s life, including their social, psychological, physical, and economic well-being.¹⁴

Over the years, Independence Care System and New York Lawyers for the Public Interest have heard numerous complaints from individuals with disabilities about the inaccessibility of health care in New York City.¹⁵ The following section provides an overview of such barriers.

Physical Barriers

Physical barriers can impede access to medical care in nearly every part of a doctor’s office or hospital, from the building entrance to the examination room.¹⁶ These physical barriers can be structural or architectural in nature, as well as result from the use of inaccessible medical equipment.

Examples of structural obstacles include restrooms without grab bars, intake areas with insufficient turning space for a wheelchair, and hallways that are too narrow.¹⁷ Many doctors’ offices in New York City also have one or more steps to the entrance, and are often located in buildings without an elevator.¹⁸ Individuals who use mobility aids, such as a wheelchair or walker, may also face barriers to obtaining comprehensive examinations and testing as a result of inaccessible equipment. They may be unable to get onto an examination table that is too high, or use diagnostic equipment that will not lower.¹⁹ Doctors may then perform an incomplete procedure, including by examining a patient while she remains in her wheelchair, despite the inadequacy of such a method.²⁰ Individuals with physical disabilities may lack the strength or balance to stand to be weighed, but providers often use weight scales that are not wide or flat enough to allow for a wheelchair or other mobility device.²¹ As a result, medical staff may altogether forego weighing the patient.²²

Studies throughout the country reveal the routine absence of accessible examination tables, weight scales and diagnostic equipment. In a national survey of people with disabilities or activity limitations, 69% of wheelchair users reported that they had difficulty using exam tables, 60% had difficulty being weighed due to inaccessible scales, 45% had difficulty using x-ray equipment (such as mammography equipment), and 43% had difficulty using medical chairs.²³ Only 1% of the providers surveyed in another study had an accessible scale.²⁴

The result of medical provider failures to ensure structural accessibility or utilize accessible equipment can range from humiliation to the development of life-threatening conditions that could have been prevented.²⁵ Lack of access to appropriate health services increases the risk that people with significant disabilities will develop additional health conditions. People with disabilities also generally experience higher rates of secondary conditions than the general population, which compounds barriers.²⁶

Communication Barriers

Physical barriers are not the only obstacles that people with disabilities confront when seeking medical care; communication barriers routinely prevent individuals with disabilities from fully understanding or relating their medical condition and treatment needs.

Deaf and hard of hearing New Yorkers regularly fail to receive a qualified sign language interpreter at doctor appointments and during trips to hospital emergency rooms. In addition, deaf or hard of hearing individuals are routinely not provided with communication devices that replace telephones, called videophones, during longer-term stays at hospitals or rehabilitation facilities.²⁷ The health disparities that result from this kind of unequal care are numerous. Research has shown them to include, “medication errors and missed diagnoses, problems during surgery and anesthesia, missed and delayed appointments, and less complete and accurate information than other patients receive.”²⁸ Basic information about health conditions is also not communicated to the deaf community. In a large survey of patients who are deaf, 62% of patients surveyed could not identify the warning signs of a stroke, 32% could not identify the risk factors of heart attack or stroke, and one in three could not define the word “cancer.”²⁹ Another startling study showed that 70% of deaf individuals said that people who are deaf could not get HIV and 50% did not know the meaning of HIV-positive.³⁰

Communication barriers similarly affect the growing population of New Yorkers who are blind or have low vision.³¹ People with visual impairments are routinely not provided with important medical information and documents in a format they can read, such as Braille or large print.³² For example, in a study of Medicare beneficiaries with severe vision impairments, rates of dissatisfaction with the quality of health care received and inadequate information provided about their health conditions were nearly double the rates seen in the general population.³³

During hospital stays, medical personnel may also fail to give blind individuals information about their surroundings, which would otherwise facilitate independence and greater comfort.³⁴ Doctors may also tell patients they are not allowed to bring their service animal into an appointment.³⁵

Barriers for individuals with developmental disabilities and mental illness also implicate a lack of appropriate and effective communication on the part of medical staff. Doctors and nurses may fail to take the necessary time to explain a procedure or treatment options to a person with a mental illness or an intellectual disability.³⁶ Medical staff may also fail to ask what steps are necessary to ensure a comfortable and safe environment for an examination, including by offering to provide additional staff to support the individual.³⁷ Data relating to the health outcomes of people with mental illness are particularly disturbing. For example, individuals with mental illness receive inferior preventive care services, such as osteoporosis screening, blood pressure and cholesterol monitoring, vaccinations, and mammography.³⁸ In high-income countries, there is a 20-year and 15-year life expectancy gap, respectively, for men and women with mental illness.³⁹

“I’ve had the experience where they talk to the aide instead of talking to me to ask what I need and how to transfer. I’m kind of feisty, so I say ‘I can answer for myself.’ But it dehumanizes me. They don’t even attempt to ask, ‘what can you do?’ or ‘why are you here?’ Sometimes you feel like it’s the elephant in the room.”

– M. Lyons, Member,
Independence Care System

Attitudinal Barriers & Lack of Training

The lack of cultural competency leads to a number of incorrect and detrimental assumptions about people with disabilities made by healthcare providers. Discriminatory perceptions have led providers to believe, for example, “that people with disabilities do not have a good quality of life; that people with developmental disabilities do not feel pain and, therefore do not require anesthesia; that people who are deaf have cognitive deficits because they may not be fluent in standard English; and that women with disabilities do not require reproductive counseling and care because they are not sexually active.”⁴¹ Research shows that these stereotypes and biases negatively affect the quality of care patients with disabilities receive.⁴²

Research reveals that physicians have not received training on the fundamental aspects of working with people with disabilities. In a 2007 survey of primary care physicians, 91% of them revealed that they had never received training on how to serve people with intellectual or developmental disabilities.⁴³ According to a national study of physicians, only 2.6% of respondents demonstrated specific awareness of the ADA.⁴⁴ Another survey of more than 500 physicians revealed that nearly 20% of respondents were unaware of the ADA and more than 45% did not know about its architectural requirements.⁴⁵ Moreover, less than a quarter of the respondents had received any training on physical disability issues in medical school, and only slightly more than a third had received any kind of training on disability during their residency.⁴⁶ However, nearly three quarters of the physicians surveyed acknowledged a need for training on these issues.⁴⁷

The following section will provide an overview of the multiple laws that shield patients with disabilities from the aforementioned discrimination that exists in medical facilities in New York City.

“The patient has the right to confidentiality. The physician should not reveal confidential communications or information without the consent of the patient, unless provided for by law...”

– American Medical Association Opinion 10.01(4), “Fundamental Elements of the Patient-Physician Relationship”⁴⁰

“Another young lady with a disability was [at the gynecologist’s office] when I was there and the doctor raced around the place saying, “Oh my god, she’s pregnant; I can’t believe it, she can’t be!” She was so loud everyone in the waiting room heard it. I was disgusted. When I went in for my appointment they did a pregnancy test on me even though I didn’t request it. When it came back negative, they said “Oh, well thank god you’re not pregnant!” I cannot even begin to tell you how upset I was, not only for myself, but for the other woman– she was a grown woman with a job – and they carried on so horribly.”

– Kim Yancy, Member, Independence Care System

Legal Framework for Providing Accessible Care

“A physician shall respect the law...”

—Principle III,
American Medical
Association’s Code of
Medical Ethics ⁴⁸

“When you have a physical disability and you’re looking for a gynecologist, you usually have to settle. Most women don’t know that the facility should be accessible, so we tend to adapt. We don’t know any better, so we settle. For example, I went to one place and the only thing that was accessible was the front door.”

– C. Cruz, Member,
Independence Care
System

Health care providers in New York City have long been legally required to make their services fully and equally accessible to people with disabilities. In addition to prohibiting the outright exclusion or segregation of people with disabilities, laws require public and private medical providers of any size to remove physical barriers, provide accessible medical equipment and communication aids, and make changes to policies and procedures. This section will provide an overview of the specific requirements of relevant federal, state and local laws that pertain to health care providers in New York City.

Anti-Discrimination Laws that Protect New Yorkers with Disabilities

Four key laws collectively prohibit discrimination against people with disabilities in virtually all healthcare facilities in New York City: Section 504 of the Rehabilitation Act of 1973 (Rehab Act), Titles II and III of the Americans with Disabilities Act of 1990 (ADA), the New York State Human Rights Law (State Human Rights Law), and the New York City Human Rights Law (City Human Rights Law).

The Rehab Act applies to programs and institutions that receive federal financial assistance, meaning that all medical care providers that receive payments from Medicaid or Medicare (excluding Part B payments) are covered by Section 504.⁴⁹ Title II of the ADA covers state and local governments, referred to as “public entities,” and includes “health services,” such as state and city hospitals and clinics, without regard to federal funding.⁵⁰ Title III of the ADA covers all “places of public accommodation,” which are generally places that are open to the public where an individual can go for goods and services.⁵¹ Thus, it covers private doctors’ offices, hospitals, and clinics.

The State Human Rights Law generally tracks the protections guaranteed to people with disabilities by the federal anti-discrimination laws described above, in particular the ADA.⁵² In New York City, the City Human Rights Law surpasses the protections of federal and state law, as confirmed by the Restoration Act of 2005.⁵³ The State and City Human Rights Laws both apply to private doctors’ offices, hospitals, and clinics as places of public accommodation.⁵⁴

Although the definition of disability under each of the aforementioned laws differs slightly, generally a person with a physical, medical or mental impairment is considered a person with a disability.⁵⁵ These laws also protect individuals from discrimination even if they are only “regarded as” having or have a “record” of a disability.⁵⁶ Finally, these laws prohibit providers from retaliating against an individual for opposing an unlawful act or practice, such as demanding a reasonable accommodation.⁵⁷

Steps to Providing Accessible Care

While each law has unique features and requirements, generally all of the laws outlined above mandate health care accessibility for New Yorkers with disabilities in similar ways. First and foremost, such laws prohibit medical providers from the outright exclusion of – or the provision of separate and unequal benefits to – people with disabilities.⁵⁸ In addition, medical providers must take action to ensure full and equal access to medical care for people with disabilities in the following three general ways: (1) by removing physical barriers; (2) by providing “auxiliary aids and services”; and (3) by making reasonable changes to policies and procedures.

First, both public and private medical providers must remove physical barriers that limit access to medical care for people with disabilities unless such a requirement would fundamentally change the nature of the program or would result in an undue financial or administrative burden.⁵⁹ For example, medical providers are required to remove architectural barriers such as steps, narrow doorways or inaccessible toilets.⁶⁰ Providers are also responsible for providing accessible medical equipment, such as exam tables that raise and lower, accessible weight scales, and accessible mammography machines.⁶¹ Medical providers are required to alter exam rooms and waiting rooms as necessary to ensure people with mobility impairments have access to these areas.⁶² Medical facilities also bear the responsibility of transferring patients to equipment when they are otherwise unable to do so independently; they must not rely on the patient’s family member, friend or aide to assist.⁶³ Providers must train staff – immediately and on an ongoing basis – on the proper transfer techniques, as necessary.⁶⁴ Beyond transfer training, providers must train staff to identify and locate “which examination and procedure rooms are accessible and where portable accessible equipment is stored.”⁶⁵

Second, in addition to removing barriers, health providers are required to offer “auxiliary aids and services,” to individuals who are deaf, blind or have low vision.⁶⁶ Auxiliary aids and services can be broadly described as aids or services that help to ensure effective communication is taking place.⁶⁷ Such aids and services include qualified sign language interpreters (on-site or through video remote interpreting), the exchange of written notes, assistive listening devices, and information provided in large print or Braille.⁶⁸ Medical providers must produce such aids and services unless it would create an undue administrative or financial burden or would fundamentally change the nature of the program or service being provided.⁶⁹ Although the language differs slightly, both Title II and III of the ADA obligate medical providers to ensure that they maintain “effective communication” with individuals with disabilities, which may include the provision of auxiliary aids and services.⁷⁰ The responsibility to provide the auxiliary aids and services rests with the medical provider, and a hospital or doctor’s office “shall not require an individual with a disability to bring another individual to interpret for him or her.”⁷¹ In addition, when a medical facility provides an accommodation, such as a sign language interpreter, it cannot ask the individual with the disability to bear the cost.⁷²

Third, medical providers must make reasonable modifications to policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability and would not result in an undue financial or administrative burden or fundamentally change the nature of the service or program.⁷³ For example, a clinic that does not normally allow animals within the facility may need to provide an exception to this policy in order to allow patients to attend appointments with their service animals.⁷⁴ Additionally, hospitals, clinics and private practitioners are required to train their medical and non-medical staff on disability competence in order to ensure that patients with disabilities are offered necessary accommodations.⁷⁵ For example, staff must take extra time to explain a procedure or course of treatment to a person with an intellectual disability, or to help position a patient with cerebral palsy who experiences spasticity or tremors during a physical examination.⁷⁶

“The provisions of this title shall be construed liberally for the accomplishment of the uniquely broad and remedial purposes thereof, regardless of whether federal or New York State civil and human rights laws, including those laws with provisions comparably-worded to provisions of this title, have been so construed.”

– Admin. Code of the City
of New York § 8-130

The Costs of Inaccessible Health Care

Compliance with the aforementioned disability anti-discrimination laws benefits medical providers and patients alike. Not only does the provision of accessible health care greatly reduce the likelihood of successful lawsuits against providers for civil rights violations, but it also ensures a safe environment for patients and employees and reduces injury-related costs. Further, medical providers can take advantage of tax incentives for making services and facilities accessible to people with disabilities. Finally, the costs to the healthcare system are reduced when patients have equal access to care.

Increased Liability Exposure

Medical providers who comply with federal, state, and local disability laws can greatly reduce their risk of liability. Conversely, facility and program inaccessibility can subject health care providers to costly litigation, including lawsuits grounded in civil rights and/or torts claims.

Health care accessibility violations, as outlined above in the Common Barriers section, are generally actionable through lawsuits in court and administrative complaints with enforcement agencies.⁷⁸ For example, medical providers who have wrongly refused to provide accessible medical equipment, or transfer patients with disabilities who cannot independently use medical equipment, have been found to be in violation of the law.⁷⁹ Similarly, doctors who refuse to provide a sign language interpreter to a deaf patient may violate the law for failing to establish effective communication with such patient.⁸⁰ Providers who refuse to allow patients with disabilities to bring their service animals into their office also violate the law.⁸¹

These failures to provide accessible services can also lead to inadequate care, misdiagnosis, improper treatment, and/or injury to the patient. Patients may recover compensatory damages for

“Patients with special needs – and their advocates – are gaining traction in obtaining accommodations to reduce their risks of substandard care... [s]ubstandard preparation puts patients at risk of harm and providers at risk of potentially indefensible allegations of negligence. Practitioners and facilities primed and equipped for special needs patients are more likely to avoid the most egregious and damaging errors (and lawsuits).”

– Pamphlet on Patient Safety, Academic Group, A Medical Malpractice Insurance Provider⁷⁷

the physical harm they suffer as a result of these violations.⁸² Even in the absence of physical harm, patients with disabilities who are subjected to inaccessible care in violation of civil rights laws can recover compensatory damages for emotional or financial harm.⁸³ Injunctive relief, such as mandating that the provider make changes to policies and procedures or provide reasonable accommodations at facilities, is another common remedy secured through lawsuits and administrative complaints.⁸⁴ Plaintiffs who prevail in lawsuits may be entitled to attorney’s fees and costs under relevant federal, state and city laws.⁸⁵ Finally, in some cases, judges may impose civil penalties to vindicate the public interest.⁸⁶

Increased Incidence of Patient & Worker Injury

Beyond limiting exposure to liability, facilities can protect the health of patients and workers, as well as reduce costs, by providing a combination of universally accessible equipment, lift and transfer equipment, and staff training on safe transfer techniques for patients with mobility impairments.

First, patient safety is enhanced by a combination of accessible equipment, proper lifting/transferring techniques, and mechanical lifts and repositioning devices. As discussed in the Legal Framework Section, medical providers should use universally accessible equipment whenever possible, but when equipment cannot be used independently by a person with a disability, it is the responsibility of the medical provider to provide assistance. When such assistance involves transfers, providers can ensure patient safety by implementing safe patient handling techniques, which incorporate lift and transfer equipment and training, as opposed to solely manual lifting techniques that are proven to be unsafe.⁸⁷ Manual lifting methods hurt patients, who “both physically and mentally feel the impact of a lift.”⁸⁸ As detailed in a report on safe patient handling, transfer technology that assists nurses and technicians can help prevent major injuries to patients, such as falls.⁸⁹ Safe patient handling also “lessens patient anxiety and enhances patient dignity and autonomy” while simultaneously reducing “the potential for patient injury (e.g., skin tears, joint dislocations, falls).”⁹⁰

In addition to protecting patient safety, health care facilities that provide accessible services not only protect their workers, but also expend less time and money. To begin with, the use of universally accessible equipment, such as adjustable exam tables, can “reduce the frequency and time required in using a lift team, lift equipment and/or providing transfer assistance from staff.”⁹¹ When such equipment is not available – and medical staff must assist with patient transfers – providers can reduce worker injuries by using the aforementioned safe patient handling methods and patient lift technology.⁹² Finally, studies of medical providers who have invested in safe patient handling programs reveal significant cost savings due to a reduction in employee injuries, worker’s compensation costs, medical/indemnity costs, and lost work days or absenteeism.⁹³

Small facilities and for-profit health care entities, such as private doctor’s offices, may not experience the same level of savings as hospitals that serve a large in-patient population that requires transfers on a regular basis. However, such entities are still responsible for making their services accessible to patients with limited mobility. These entities can take advantage of tax incentives for accessibility improvements to buildings and services under the “Disabled Access Credit.” This credit allows small businesses – defined as those with thirty or fewer employees or total revenue of \$1 million or less⁹⁴ – to apply for a tax credit of up to \$5,000 or half of eligible expenses per year.⁹⁵ Eligible expenses include barrier removal, whether facility or communication based, and provision or modification of equipment.⁹⁶ Businesses of any size can also utilize a tax deduction of up to \$15,000 per year for removing barriers in facilities.⁹⁷

Increased Costs to the Healthcare System

The costs of inadequate care extend beyond calculations of healthcare facility savings and limited liability exposure; our healthcare system incurs significant costs due to unequal access for people with disabilities. When patients with disabilities receive inadequate health care, it may mean that a diagnosis is missed and the disease progresses, which can cost more to treat. For example, late diagnosis of breast cancer, which occurs at a higher rate for women with disabilities due to barriers to mammography,⁹⁸ is more costly to treat and takes more lives than when it is caught early.⁹⁹ Inaccessibility and barriers to care may also lead people with disabilities to more frequently utilize emergency departments for preventive services than the general population,¹⁰⁰ all at a greater cost.¹⁰¹ A national survey calculated that receipt of non-urgent care in an emergency department was seven times more expensive than receipt of the same services in a health center.¹⁰² Providing quality accessible care to people with disabilities in all health care settings would eliminate these high costs to the healthcare system.

“[T]raining staff to properly assist with transfers and lifts, and to use positioning aids correctly will minimize the chance of injury for both patients and staff.”

–Department of Justice
Guidance, Access To
Medical Care For Individuals
With Mobility Disabilities

Case Study: Accessible Cancer Screening Services for Women with Disabilities

Barriers to health care disproportionately affect women with disabilities. While they appear everywhere, including routine exams and procedures, when such barriers prevent proper screening for cancer, the consequences can be deadly.¹⁰³ We must eliminate this insidious inequality to protect the nearly half a million women with disabilities living in New York City who should be receiving regular gynecological care, the vast majority of whom should also be receiving annual mammograms.¹⁰⁴

Health disparities for women with disabilities are startling, and they can lead to delayed or missed diagnoses of breast or cervical cancers. For example, women with disabilities have the same incidence of breast cancer as women without disabilities, yet they are nearly one-third more likely to die from it.¹⁰⁵ When data from a national survey was analyzed for a subsection of the disability community comprising women with major mobility impairments, researchers found that these women were nearly 20% less likely to have received a mammogram in the last two years.¹⁰⁶

Disparities for women with mental disabilities are even starker; after adjusting for comorbid

conditions, women with mental illness were more than 30% less likely to receive a mammogram¹⁰⁷ and only 12% of women with intellectual disabilities received timely mammograms.¹⁰⁸ Mortality rates for women with disabilities due to breast and cervical cancer could be significantly reduced if timely screening and treatment was made accessible for all women.¹⁰⁹

This section will identify the multiple obstacles women with physical disabilities face in accessing breast cancer screening and gynecological care, and reveal how those barriers have been dismantled at a handful of private and public health facilities in New York City. While these changes have focused solely on the barriers encountered by women with physical disabilities, similar changes must be made to eliminate barriers encountered by women who, for example, are deaf or hard of hearing, or have mental disabilities. Medical providers must eliminate obstacles and ensure that women with disabilities receive quality, accessible care in accordance with civil rights laws.

“A solid body of evidence confirms disparities in care – especially cancer screening services – for women with disabilities. For example, our studies using nationally representative databases find that women with physical disabilities are significantly less likely to receive Pap tests to screen for cervical cancer; disparities in mammography screening also exist, although patterns of these differences vary by disability type. These large national surveys typically do not reveal why disparities exist, but our studies using focus groups and in-depth individual interviews provide clues. Clinicians may erroneously think that women with disabilities are sexually inactive and therefore not at risk of exposure to the human papillomavirus linked to cervical cancer. Women with physical disabilities tell me that their clinicians often do not have accessible examining tables and examine the women while they sit in their wheelchairs – hence, no Pap test! Our research finds that these disparities in care can increase mortality and morbidity and also worsen quality of life of women with disabilities.”

– Lisa I. Iezzoni, MD, MSc, Director of the Mongan Institute for Health Policy at Massachusetts General Hospital & Professor of Medicine at Harvard Medical School

Improving Cancer Screening Accessibility in New York City

The vast majority of medical facilities in New York City have work to do to come into compliance with disability anti-discrimination laws. However, incremental improvement in accessibility is already underway thanks to the efforts of one New York City advocacy organization. These efforts must not remain limited to this tiny sliver of the healthcare community – all medical providers must ensure that patients receive the accessible care to which they are entitled.

Independence Care System (ICS) operates a nonprofit Medicaid managed long-term care plan specifically designed for adults with physical disabilities and chronic illnesses. The majority of ICS's members are women, and they are all recipients of Medicaid. In response to concerns expressed by its members about their negative experiences seeking health care over the years – they had no fully accessible location at which they could receive breast and gynecological care – ICS decided to take action. With funding from the Greater New York City Affiliate of Susan G. Komen for the Cure® since 2008, ICS has been developing and implementing its Breast Cancer Screening Project for Women with Physical Disabilities.¹¹⁰ Recently, with a grant from the Baisley Powell Elebash Fund, ICS expanded its Women's Health Access Program to include gynecological care.

In the first year, ICS identified two provider sites with which to partner: New York Presbyterian Hospital-Columbia University Medical Center, a provider site of the Columbia University Breast Cancer Screening Partnership Program, and the Breast Examination Center of Harlem, a program of Memorial Sloan Kettering Cancer Center. Beginning in the fourth year of the project, ICS expanded its advocacy to include gynecological care, as well as breast cancer screening, at two additional facilities: the Morrisania Diagnostic and Treatment Center in the Bronx, a clinic affiliated with Lincoln Medical Center, and Woodhull Medical Center in Brooklyn, at which ICS plans to fully operationalize a program in the coming year. The two most recent partnerships are particularly significant given that they are with Health and Hospitals Corporation facilities (i.e. public hospitals), where most ICS members, as well as underserved New Yorkers, receive their care. Through its two projects, ICS has helped secure more than 200 accessible breast and gynecological cancer screenings for its female members with disabilities.

ICS's projects reveal how a commitment to accessibility from health care institutions can lead to the successful elimination of barriers encountered by women with disabilities. In conducting these projects, ICS identified three major areas in which providers had to make changes to ensure accessibility. The first step was for facilities to identify and eliminate physical barriers to care. The second step was for partner facilities to conduct, with ICS's assistance, disability awareness and sensitivity training for doctors, nurses and staff. Finally, partner facilities altered the coordination and intake process for patients with disabilities to reduce inefficiencies and increase comfort. Each of these steps was critical to ensuring that women with mobility impairments had a positive experience and received comprehensive cancer screening. The fundamental tenets of these projects demand replication by other New York City healthcare facilities.

“No one wants to get a mammogram. But if you're going to be treated like you're a problem because of your disability, it's even more of a hassle and no one is going to want to go.”

– Marilyn E. Saviola, Vice President of Advocacy and the Women's Health Access Program, Independence Care System

Remedying Physical Barriers & Inaccessible Equipment

Through both its breast and gynecological screening projects, ICS found a wide array of physical and/or structural barriers in partner locations. Notably, solutions were often readily available and did not incur great cost. As part of the projects, ICS met with clinical and executive staff at each facility to discuss the most prevalent barriers, including those identified by ICS members through surveys, and together made a plan to improve the facility's physical space, procedures and practices to ensure accessibility.

Mammography Project

Equipment barriers were commonplace at the breast cancer screening project partner facilities. For example, mammography machines were often inaccessible for ICS members with mobility impairments who could not stand or hold their arms high enough. Other ICS members experienced uncontrollable movements and could not keep their arms steady in the required position, which made it difficult to successfully complete a mammogram. Although the ideal solution would be universally designed mammography equipment,¹¹¹ simple interim solutions helped address these barriers; positioning aides, such as Velcro straps, were used to support the women's arms during the test and additional technologists assisted as necessary to help with positioning.¹¹² ICS's Nurse Educator accompanied the project participants to their appointments and shared helpful techniques with the technologist regarding positioning and wheelchair placement. She also instructed the technologist on what other assistance was necessary to allow for an accurate and comfortable mammogram, such as using a lumbar pillow for back support. Women who visit the partner facilities are now able to stay in their wheelchair or, in the case of one partner facility, to transfer to an adjustable mammography chair, depending on what is most comfortable and can provide the best screening image.

Design and structural barriers also contributed to concerns about ICS members' ability to fully access care. In one facility the design of the mammography suite presented a major problem; the room had a console in the middle of the floor that obstructed the path to the mammography machine for women in power wheelchairs and scooters. In response, the facility reconfigured the area, moving the console to the edge of the room. This fix allowed for additional space and ensured that women in wheelchairs were no longer denied access to mammograms.

Gynecological Project

Physical barriers were similarly present in partner gynecological care facilities. Equipment, such as examination tables and weight scales, initially were not fully accessible to ICS members who participated in the project. This discovery was consistent with experiences the women had previously had at other facilities. The majority of ICS members who participated in the project had never had an accessible table available to them; the primary reason cited for not having previously received a gynecological exam was that the examination table was too narrow, high, and/or flat.¹¹³ ICS members reported previously having not received full examinations or procedures.¹¹⁴

In response to these barriers, Morrisania obtained an accessible weight scale and Hoyer lift for its exam room, as well as purchased and installed accessible features for its height adjustable exam table. Such features comprised adjustable stirrups, leg supports, a movable headrest, and side rails. The modified tables, in particular, completely changed the experience for the ICS members. One ICS member explained that after years of visiting the doctor, her visit to Morrisania was her first fully accessible gynecological experience.¹¹⁵

“I have cerebral palsy. [At other places,] sometimes they used a q-tip to examine me because of my spasticity. I was worried about the actual reading, and whether they could really check for cancer cells because they just swabbed the surface, and didn't swab my cervix. I don't know if it was because I couldn't relax enough – I felt like I was going to fall off the table.”

– M. Lyons, Member,
Independence Care System

Educating Staff to Address Provider Misconceptions & Ignorance

Provider bias and inadequate counseling prevents women with disabilities from seeking and receiving comprehensive cancer screening.¹¹⁶ Both ICS projects revealed gaps in knowledge and counseling for members that required sensitivity and cultural competency training to address.

In addition to misconceptions about mammograms, facility inaccessibility and the failure of providers to properly counsel women with disabilities contributed to ICS members' reluctance to get screened. ICS members were often completely unaware that they needed to get a mammogram because their provider had previously failed to recommend it to them or told them they could not receive one since they were in a wheelchair.¹¹⁷ ICS members were also unable to find an accessible and welcoming location where they could receive the screening.¹¹⁸ ICS reported that their members were reluctant to get mammograms because they "believe that having one significant medical condition precludes their having another; fear that because of their disabilities they will be unable to endure the exam; or feel overburdened by multiple medical appointments."¹¹⁹ The inconvenience of mammograms is compounded by the disability-related barriers that women face every day, such as a lack of transportation or the need to coordinate home care services. These additional barriers make it even more critical that providers emphasize the importance of breast cancer screening to women with disabilities. To address this gap in knowledge, ICS organized workshops and instituted a one-to-one outreach program where staff called hundreds of women to educate them on the importance of mammograms and early detection.¹²⁰ Once the women heard about ICS's breast cancer screening project, many were relieved that they could actually receive the testing they needed in a facility that was accessible to them.¹²¹

ICS members had also received inadequate gynecological care because of provider bias. For example, several ICS members reported not being asked by their gynecologist whether they were sexually active.¹²² Woman who participated in the gynecological project also reported that their previous physician was insensitive to their needs. The majority of ICS members surveyed who received a pelvic exam and Pap smear before joining the project reported that they did not go back because it was too traumatic.¹²³ ICS members experienced trauma from the extreme difficulty encountered in trying to get on the exam table, not being able to fit their legs into non-adjustable stirrups, and being made to feel as though they were the problem.¹²⁴ One woman reported that her previous gynecologist had threatened to leave if she did not stop the uncontrollable leg spasms she experienced due to her disability.¹²⁵ The majority of members reported that their gynecologist had never explained the reason for the test, how it would be performed, or when they could get the results.¹²⁶

To address the barriers identified in both the breast and gynecological care projects, ICS implemented a Disability Awareness and Sensitivity Training program for all partner facility staff, including clerical, support, clinical and administrative workers. The training included elements of cultural competency and technical skills for working with women with disabilities. In particular, the training emphasized the creation of a patient-centered environment through sensitivity to the woman's needs and a consciousness of how provider misconceptions may interfere. For example, in the context of gynecological care, doctors and other staff were instructed not to assume a woman with a disability does not want to have children, to listen to the woman's suggestions for the best positioning, and to thoroughly explain all procedures before performing them. The gynecologist at Morrisania incorporated this knowledge into her practice and ICS members note that when this gynecologist sees them, they feel they are finally being respected fully as women, as human beings, in a way that many providers have previously failed to do.¹²⁷ This kind of training must be replicated in other healthcare facilities to ensure that providers are providing culturally competent care to their patients with disabilities.

“[When I went to the gynecologist through the ICS program] it was the first time anyone had ever asked me, ‘Would you like to have a child?’ I am 37 years old and no one has ever asked me anything like that.”

– Kim Yancy, Member,
Independence Care
System

“My first time in the ICS program, everything was in one room so I didn’t have to undress and come in through the back door. I usually have a real hard time with spasticity, but the chair lift worked and I was able to get on the chair pretty much by myself. That the table actually came down to me – that made a huge difference. She did the examination the way it should be done. I’m 49 years old and that was the first time I had a totally accessible experience.”

– M. Lyons, Member,
Independence Care System

Creating Procedures to Increase Efficiency & Accessibility

The final area addressed at partner facilities through the ICS projects was altering how the facilities scheduled appointments and conducted patient intake. Prior to these adjustments, ICS members had encountered numerous problems with insufficient reasonable accommodations and inefficiency when seeking health care at facilities.

ICS encouraged each partner facility to add a functional assessment section to the intake forms with a series of simple questions, such as whether the woman could transfer or raise her arms, to evaluate what accommodations may be necessary.¹²⁸ This form was filled out and sent to the facility in advance of the appointment to allow the facility staff to plan accordingly for the appointment. For example, the staff could ensure that an extra technologist was available, or additional time was scheduled, as necessary. The form remained in the patient’s chart so the facility and physician could reference it in the future, as opposed to repeatedly asking the patient to rehash her needs every time she visited. Making procedural accommodations of this sort also prevented women with disabilities from experiencing extensive delays which could cause them to miss their transportation, and take them hours to reschedule.¹²⁹ These accommodations also meant that ICS members did not have to worry that their home care worker would go off duty and be unable to accompany them home, or that they would be forced to pay for the additional time.

Another simple, yet helpful, procedural change implemented through the ICS program was to ensure that patients could receive as many elements of care as possible in the same location. For example, when relevant, the facilities took the patient’s vitals and weight in the same room in which they were being seen for the mammogram or gynecological screening. Of particular importance, the facilities made changes so that women who used mobility aides were able to change into the patient gown in the mammography suite for breast exams, or the exam room for gynecological visits. This adjustment allowed for smoother transitions and afforded ICS members more privacy; previously the women had to change in one location and move to another using their mobility aid, while trying with great difficulty to keep themselves covered. With this very minor adjustment, women with disabilities experienced a much more comfortable and private visit. For mammograms, this procedural adjustment also reduced the time needed for an exam.¹³⁰

The vast majority of barriers that ICS members identified were successfully addressed by partner providers; however, some providers expressed an unwillingness to implement recommended changes out of misplaced concerns about liability. For example, one provider was reluctant to use positioning aids, specifically Velcro straps, for fear that institutional policies on restraints prohibited the use of such devices.¹³¹ These liability concerns were unsubstantiated. Laws and regulations prohibiting the improper use of restraints, which were passed in response to patient abuse and neglect in mostly in-patient settings, do not apply to positioning aids used for routine medical screenings and diagnostic tests in outpatient settings.¹³² In fact, most statutory and regulatory definitions of restraint explicitly exclude the use of assistive devices.¹³³

Clearly, not only do medical providers need to commit to making their services accessible, but they could also benefit from additional guidance and oversight from various entities to ensure that their practices comply with the law.

“Where can other women with disabilities [who are not ICS members] go to get these mammograms and pap smears done and be comfortable? There’s a lot of people out there who don’t get a mammogram or a pap smear...”

– Esther J., Member, Independence Care System

Next Steps for Accessibility Across New York City

Five and a half months into its Breast Cancer Screening Project, ICS was still struggling to find a medical provider that was willing to partner with them. Facilities displayed “reluctance, resistance, discrimination, and outright hostility” when ICS approached them about collaborating to provide accessible services.¹³¹ These responses demonstrate a profound disrespect and lack of understanding of medical providers’ legal, ethical, and moral obligations to care for women with disabilities. Sadly, this is the rule rather than the exception in health care facilities across New York City.

New York City has a long road ahead to ensure that all of its healthcare facilities provide accessible care to people with disabilities. Barriers and biases that block men and women with all types of disabilities from obtaining accessible care, must be eliminated in health care settings of all sizes and types. But the accomplishment of ICS’s projects – the long overdue accessible care for its members – begs for replication. Medical providers and policymakers have a legal and moral obligation to ensure that New Yorkers are not subjected to inferior care on account of their disability.

“Solutions will require multiple approaches, including ensuring that facilities and equipment are fully accessible to women with diverse disabilities and that clinicians are trained in “disability competency.” Trainers in disability awareness could learn volumes from programs such as Independence Care System, with its multifaceted care model that ensures women with disabilities receive the services they desire and need to maximize their health and quality of life.”

– Lisa I. Iezzoni, MD, MSc, Director of the Mongan Institute for Health Policy at Massachusetts General Hospital & Professor of Medicine at Harvard Medical School

Recommendations to Providers & Policymakers

People with disabilities encounter a multitude of obstacles to comprehensive, quality health care in facilities of all sizes in New York City. These barriers include architectural and communication barriers, inaccessible equipment, and provider bias. The effects of these obstacles to care are profound; inaccessible health care negatively impacts nearly every aspect of an individual's life, and leads to significant disparities.

New York City hospitals and clinics have an opportunity to take the lead nationwide in providing accessible health care, in compliance with applicable law, to their patients with disabilities. Public and private medical providers, city and state lawmakers, and state agencies all have key roles to play in ending healthcare disparities for people with disabilities. We recommend the following actions be taken immediately:

New York City Medical Provider Recommendations

Medical providers must develop and implement a comprehensive plan for providing accessible care to people with disabilities. The plan should include:

- **The creation and dissemination of a system-wide non-discrimination policy, with accompanying protocols and procedures.** Facilities must come into compliance with disability anti-discrimination laws by providing patients with disabilities with equal access to care. Facility and system administrators must create and implement a policy and accompanying protocols to ensure compliance at all levels. Facilities must also designate a point person to coordinate and ensure the implementation of such policies and protocols. Such protocols must include a grievance procedure for patients with disabilities who are denied accessible care.
- **The development and implementation of mandatory, system-wide disability competency provider trainings.** Facilities must develop a mandatory system-wide training, or series of trainings, in consultation with experts in disability competency. Such training/s must cover the following core concepts: disability awareness and sensitivity; overarching legal obligations to provide accommodations; protocols for positioning and transferring patients with disabilities; the requirement to provide additional staff as needed for certain procedures and tests; and the requirement to fully treat and counsel patients with disabilities, including about basic health information such as when and how to obtain preventative screenings.
- **The acquisition of accessible equipment and removal of communication and architectural barriers.** Providers must purchase accessible equipment, including mammography machines, weight scales, examination tables, and Hoyer lifts. Providers must also remove existing barriers, such as by widening doors and installing grab bars, and providing sign language interpreters and materials in alternative print. Finally, providers must utilize positioning aids and supports to assist women with disabilities as needed to facilitate screenings and procedures.
- **Coordinate care and maintain good data and records.** Providers must ensure that the process of scheduling appointments, requesting and providing accommodations runs smoothly for patients with disabilities. Such process shall include a functional assessment prior to the appointment, which would then be stored in the patient's file and referenced prior to each appointment.

“Some of our members have trouble breathing when they have to lay completely flat. They just can’t breathe like that. So it is traumatic when they are on a regular table. The table at Morrisania, has a head rest that raises so they can breathe and relax. It is a relief for them that they can finally breathe at a doctor’s office. The table also has side rails so women do not feel like they are going to fall off. All of these things make it possible to do the test. The table is one of the most important things.”

– Jane Nietes, Nurse Educator,
Independence Care System

“The provision of culturally competent care is required by current laws, regulations and accreditation agencies’ standards. At HHC, we ascribe to the belief that the provision of culturally competent care:

- Is an essential component of HHC’s mission, vision and values;
- Leads to improvements in quality and patient safety;
- Is necessary to accommodate changing patient and neighborhood demographics;
- Reduces health disparities; and most importantly,
- Is the right thing to do.”

– New York City Health and Hospitals Corporation

Comments before New York City Council Committees on Health and Civil Rights
Delivered by Caroline M. Jacobs, Senior Vice President, Safety and Human Development

New York City Health & Hospitals Corporation (HHC) Recommendations

In addition to the aforementioned recommendations that pertain to medical providers, HHC should:

- **Convene a task force to develop detailed guidance on ensuring accessibility in healthcare facilities in compliance with existing law.** HHC should assemble a task force to develop technical assistance to guide facilities on how to ensure their programs and services are accessible. The task force should include a representative from each facility, experts, stakeholders, and people with disabilities who can advise on effective policy and training, accessible equipment procurement, architectural modifications, accessible communication, and disability specific medical protocols (e.g. follow-up after mammograms that produce limited views due to inaccessibility of screening). The task force should issue reports, guidance, and recommendations to help facilities comply with disability rights laws in a consistent manner. Each facility’s representative should ensure implementation of the guidance issued by the taskforce. Quarterly, the facility coordinators should meet to review best practices, implementation, and discuss innovative approaches to making their facilities accessible. Stakeholders, including people with disabilities and the public at large, should also be invited to participate in the quarterly meetings to provide their feedback and suggestions.
- **Develop and disseminate a patient and provider survey regarding the accessibility of HHC facilities and services.** The survey should assess the knowledge of providers about their obligations under the ADA and state and city anti-discrimination laws. Providers should be asked about all types of accommodations and how they provide care to people with disabilities. Patients should also be surveyed to understand whether they are receiving the care they need. HHC should use this data to target, through trainings, the gaps in knowledge that staff may display, as well as to inform facilities about ways in which they must make services accessible.

New York City Council Recommendations

- **Pass a comprehensive resolution urging New York City hospitals and medical providers to comply with existing federal, state, and local disability anti-discrimination laws.** The City Council is uniquely situated to communicate the importance of providing accessible health care to all New York City residents, including individuals with disabilities. The City Council should pass a resolution which:
 - o ***Directs New York City medical providers to, at a minimum:***
 - Comply with existing federal, state, and city laws regarding people with disabilities, as well as relevant regulations and guidance as issued
 - Develop a guiding non-discrimination policy, designate a point person to coordinate its implementation, and create protocols and procedures staff must follow to ensure facility accessibility
 - Eliminate existing communication, attitudinal, and physical barriers to care, alter physical space as necessary, and purchase accessible equipment
 - Provide mandatory disability competency, awareness, and sensitivity training
 - Notify patients with disabilities of their rights under disability anti-discrimination laws and how to file a complaint
 - o ***Directs the New York City Health and Hospitals Corporation to, at a minimum, in addition to the aforementioned recommendations:***
 - Convene a task force to develop detailed guidance for health care facilities on how to make services accessible in compliance with existing law
 - o ***Urges the New York State Department of Health to, at a minimum:***
 - Issue and enforce detailed guidance to healthcare facilities as to their legal obligations regarding making programs and facilities accessible to people with disabilities
 - Create a robust and accessible complaint process with defined follow-up procedures
 - Amend facility requirements on training and intake to include disability
 - o ***Urges the New York State legislature to, at a minimum:***
 - Pass legislation requiring that medical facilities procure accessible medical equipment in compliance with anti-discrimination laws and regulations
 - Issue notice requirements for all healthcare facilities to notify patients of their right to accommodations and accessible care

“I would hope that the doctor would see me as a person, but I think they just see the wheelchair. They don’t see us as people because they think it will take more time. But with [the ICS Project gynecologist], I automatically felt more comfortable. I felt like she actually saw me as a woman coming for an appointment to be healthy.”

– M. Lyons, Member, Independence Care System

- **Include funding in the budget, with terms and conditions, to assist capital improvements at HHC facilities that are designed to increase accessibility for people with disabilities.** At a minimum, HHC facilities should procure Hoyer lifts and, accessible mammography machines, exam tables, and weight scales. As a “term and condition” of HHC funding, the City Council should require that HHC procure all goods in compliance with anti-discrimination laws.
- **City Council should convene annual oversight hearings on the accessibility of medical services and the needs of people with disabilities.** Annual hearings on this issue should be used to assess HHC’s progress toward making facilities accessible and whether private providers are serving individuals with disabilities equally. Facilities should be asked to provide information regarding staff training, procurement policies, compliance with the ADA, and the services provided to people with disabilities.

“People jokingly tell me that they would gladly keep the weight from their youthful pasts. Exact weight, however, can matter. A woman whom I interviewed for a research project on women with physical disabilities who develop breast cancer has used a wheelchair since a spinal cord injury in her late teens. Twenty-five years later with breast cancer, her oncologist needed to know her weight to set her chemotherapy dose; however, the academic medical center where she received care did not have an accessible scale. To find her weight, her oncologist scooped her up from her wheelchair and stepped onto a scale holding her in his arms.”

— Lisa I. Iezzoni, MD, MSc, Director of the Mongan Institute for Health Policy at Massachusetts General Hospital & Professor of Medicine at Harvard Medical School

“ICS’s GYN project was the first time I’ve been accurately weighed.”

—M. Lyons, Member, Independence Care System

New York State Department of Health Recommendations

- **Issue a detailed administrative directive to all medical facilities regarding their obligation to provide accessible services to people with disabilities, and ensure facility compliance with said directive and disability anti-discrimination laws.** DOH should issue a detailed directive to medical facilities operating in NYS instructing them on how to come into compliance with disability anti-discrimination laws by making facilities physically accessible, providing reasonable accommodations, and training staff on disability competency and techniques for providing assistance to patients with disabilities. The directive should also include clarification that positioning and support aids are not considered “restraints” when used to position patients with disabilities during routine exams or procedures. The directive should instruct providers to follow the DOJ and Access Board’s regulations and guidance regarding access to medical care for people with disabilities as issued. DOH should use its authority to ensure compliance with anti-discrimination laws and the specific components of this directive.
- **Create a robust and accessible complaint process with defined follow-up procedures.** DOH should create and implement an accessible complaint process that includes a clearly defined follow-up procedure, including investigation of non-compliant facilities. Complaints received through such process should be reviewed when making decisions regarding

“Being weighed has always been an issue. They say, ‘let’s do it approximately.’ Before they prescribe medication they should know my weight, but sometimes they’ll say ‘let’s try this dose and you can come back to change it if we need to.’ Sometimes they’ll just ask how long ago I was weighed and how much, and just write that down instead of weighing me. I’m not sure if it’s because they don’t have the right equipment, or because they don’t want to be bothered. When you’re a disabled person and you go to get care, it will take more time. But we live in a society where everything has to be done quickly. Unfortunately, it’s going to take an extra minute for people with disabilities.”

– M. Lyons, Member, Independence Care System

the selection of facilities for compliance review. Information about the complaint process, including how and where to file a complaint and the process for investigation, should be conspicuously posted on the DOH’s website and on materials distributed to patients.

- **Amend facility requirements on training and intake to include disability.** DOH should amend existing requirements for intake processes at in- and out-patient facilities to include a disability accommodations needs assessment. This assessment should give the patient an opportunity to identify and request reasonable accommodations so the facility can take steps to make care accessible (i.e. if patient identifies that she cannot hold her hands above her head, facility will note that positioning aides or extra technologist must be available for exam). DOH should also amend facility quality assurance training requirements to include mandatory ongoing disability competency training for all staff. DOH should exercise its authority to the fullest extent possible to ensure that medical providers practicing in NYS are properly trained on how to provide equal care to people with disabilities. As mentioned in the “Medical Providers Recommendations,” such training/s, which should be developed by the facility, must cover several concepts that are fundamental to providing accessible care.

New York State Legislature Recommendations

- **Pass legislation that requires all medical facilities to provide notice to patients of their rights to accessible care.** Medical facilities must be required to clearly post throughout facilities, and make available in accessible formats, notices regarding the availability of – and process by which to request – disability accommodations. This notice should be conspicuously posted on each healthcare facility’s website, in e-mail notifications to patients, and in brochures and other patient materials.
- **Pass legislation requiring procurement of accessible medical equipment by healthcare facilities.** The legislature should pass legislation requiring that all medical equipment procured by healthcare facilities and clinics comply with anti-discrimination laws and regulations, and that all newly purchased equipment follow principles of universal design and be accessible to people with disabilities.

“It’s important because my mother had breast cancer and if I don’t get that mammogram I could get cancer and not know it. If I get the mammogram maybe I could catch it in time. I like to have my mammogram every year.”

– Esther J., Member,
Independence Care System

Endnotes

- ¹ See, e.g., NAT'L COUNCIL ON DISABILITY, THE CURRENT STATE OF HEALTH CARE FOR PEOPLE WITH DISABILITIES (2009), http://www.ncd.gov/rawmedia_repository/0d7c848f_3d97_43b3_bea5_36e1d97f973d?document.pdf; see also, JUDY PANKO REIS ET AL., IT TAKES MORE THAN RAMPS TO SOLVE THE CRISIS OF HEALTHCARE FOR PEOPLE WITH DISABILITIES 7 (2004), www.tvworldwide.com/events/hhs/041206/PPT/RIC_whitepaperfinal82704.pdf.
- ² See, e.g., M. A. Nosek and C. A. Howland, *Breast and Cervical Cancer Screening Among Women with Physical Disabilities*, 78 ARCHIVES OF PHYSICAL MED. & REHABILITATION S39 (1997).
- ³ See, e.g., Ellen P. McCarthy et al., *Disparities in Breast Cancer Treatment and Survival for Women with Disabilities*, 145(9) ANNALS OF INTERNAL MED. 637 (2006).
- ⁴ REIS ET AL., *supra* note 1, at xiii ("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.").
- ⁵ In New York City, only 4% of children between 5 and 17 years old have a disability, while well over a third of the population over 65 years old have a disability. U.S. CENSUS BUREAU, 2011 AM. CMTY. SURVEY, DISABILITY CHARACTERISTICS NEW YORK CITY, NEW YORK, tbl.S1810 (2011).
- ⁶ N.Y.C. DEP'T OF CITY PLANNING, NEW YORK CITY POPULATION PROJECTIONS BY AGE/SEX & BOROUGH, 2000-2030 (2006).
- ⁷ U.S. CENSUS BUREAU, *supra* note 5, at tbl.S1810.
- ⁸ *Id.* at tbl.B18135.
- ⁹ *Id.* at tbl.B18130.
- ¹⁰ *Id.* at tbl.B1811.
- ¹¹ *Id.* at tbl.B18130.
- ¹² Independence Care System, 2011 Community Breast Health Grantee: Final Report 2 (Apr. 30, 2012) (unpublished grant report) (on file with Independence Care System) [hereinafter Independence Care System, Final Report].
- ¹³ AM. MED. ASS'N, CODE OF MEDICAL ETHICS [hereinafter CODE OF MEDICAL ETHICS], available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page> (last visited Oct. 22, 2012).
- ¹⁴ M.T. Neri & T. Kroll, *Understanding the consequences of access barriers to health care: experiences of adults with disabilities*, 25 DISABILITY & REHAB. 85, 94 (2003).
- ¹⁵ In addition to complaints received through its intake line, NYLPI has heard stories of inaccessible care from individuals with disabilities during education and outreach events. ICS has received complaints from its members through group discussions, education and outreach events, and from the participants in the Women's Health Access Program.
- ¹⁶ See Catherine Leigh Graham & Joshua R. Mann, *Accessibility of Primary Care Physician Practice Sites in South Carolina for People with Disabilities*, 1 DISABILITY & HEALTH J. 209, 212 (2008).
- ¹⁷ JUNE ISAACSON KAILES ET AL., CTR. FOR DISABILITY ISSUES & THE HEALTH PROFESSIONS, HEALTH CARE (CLINIC / OUT-PATIENT) FACILITIES ACCESS 7, 8, 13 (2d ed. 2009), [http://www.cdihp.org/briefs/4.%20Brief-Health%20Care%20\(outpatient_clincs\)%20Facilities%20-%20FINAL%20Edition%202_1.5.09.pdf](http://www.cdihp.org/briefs/4.%20Brief-Health%20Care%20(outpatient_clincs)%20Facilities%20-%20FINAL%20Edition%202_1.5.09.pdf).
- ¹⁸ NYLPI has heard such complaints expressed by numerous New Yorkers, particularly when it comes to specialty care. These barriers can be further compounded by the absence of accessible providers within provider networks or HMOs.
- ¹⁹ DISABILITY RIGHTS EDUC. & DEFENSE FUND, DISABILITY HEALTHCARE ACCESS BRIEF 1-2, http://www.dredf.org/healthcare/Access_Brief.pdf.
- ²⁰ See, e.g., Lisa I. Iezzoni et al., *Physical Access to Barriers to Care for Diagnosis and Treatment of Breast Cancer Among Women with Mobility Impairments*, 37 ONCOLOGY NURSING FORUM 711, 714 (2010) [hereinafter Iezzoni, et al., *Physical Access to Diagnosis and Treatment of Breast Cancer*]. When accessible tables are not available in a facility, doctors may also be reluctant to suggest necessary procedures or fully examine a patient. Kristi L. Kirschner et al., *Structural Impairments That Limit Access to Health Care for Patients with Disabilities*, 297 JAMA 1121, 1121 (2007).
- ²¹ JUNE ISAACSON KAILES ET AL., CTR. FOR DISABILITY ISSUES & THE HEALTH PROFESSIONS, IMPORTANCE OF ACCESSIBLE WEIGHT SCALES (2004).
- ²² See, e.g., U.S. DEP'T OF JUSTICE, AMERICANS WITH DISABILITIES ACT: ACCESS TO MEDICAL CARE FOR INDIVIDUALS WITH MOBILITY DISABILITIES 18 [hereinafter U.S. DEP'T OF JUSTICE, ACCESS TO MEDICAL CARE], available at http://www.ada.gov/medcare_ta.htm (last visited Oct. 22, 2012) ("A patient's weight is essential medical information used for diagnostics and treatment. Too often, individuals who use wheelchairs are not weighed at the doctor's office or hospital, even though patients without disabilities are routinely weighed, because the provider does not have a scale that can accommodate a wheelchair.").
- ²³ JUNE ISAACSON KAILES, CTR. FOR DISABILITY ISSUES & THE HEALTH PROFESSIONS, REHAB. ENGINEERING RES. CTR. ON ACCESSIBLE MED. INSTRUMENTATION, 5 "G's:" GETTING ACCESS TO HEALTH CARE FOR PEOPLE WITH DISABILITIES (v. 1 2008), <http://www.cdihp.org/Five%20Gs%20apr21.pdf>.
- ²⁴ Graham & Mann, *supra* note 16, at 212.
-

²⁵ See Kirschner et al., *supra* note 20, at 1122.

²⁶ NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 23 (citing HENRY J. KAISER FAMILY FOUND., HEALTHCARE FOR PEOPLE WITH DISABILITIES (2004), <http://www.kff.org/medicaid/7202.cfm>).

²⁷ NYLPI has represented deaf clients who have encountered numerous communication barriers in all types of health care facilities, including at hospitals and rehabilitation facilities in New York City.

²⁸ Lisa I. Iezzoni et al., *Communicating About Health Care: Observations from Person Who Are Deaf or Hard of Hearing*, 140 ANNALS OF INTERNAL MEDICINE 356, 360 (2010).

²⁹ NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 71 (citing Helen Margellos-Anast et al., *Cardiovascular disease knowledge among culturally Deaf patients in Chicago*, 42 PREVENTIVE MED. 235 (2006); SINAI HEALTH SYS. AND ADVOCATE HEALTH CARE, IMPROVING ACCESS TO HEALTH AND MENTAL HEALTH FOR CHICAGO'S DEAF COMMUNITY: A SURVEY OF DEAF ADULTS (2004)).

³⁰ NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 71 (citing M.F. Goldstein, et al., *An HIV Knowledge and Attitude Survey of Deaf U.S. Adults*, 22(1) DEAF WORLDS 163 (2006)).

³¹ Aging is one of the leading causes of vision loss. NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 73 (citing R.N. Bailey et al., *Visual Impairment and Eye Care Among Older Adults – Five States, 2005*, 55 MORBIDITY & MORTALITY WEEKLY REPORT 1321, 1321–26 (2006)). As the population ages, the number of people who are blind and the number of people with vision impairments living in the U.S. is projected to increase by an astonishing 70-percent between 2009 and 2020. NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 73 (citing Nat'l Eye Inst., *Causes and Prevalence of Visual Impairment Among Adults in the United States*, 122 ARCHIVES OF OPHTHALMOLOGY 477, 477-85 (2004)).

³² See EQUAL RIGHTS CTR., ILL-PREPARED: HEALTH CARE'S BARRIERS FOR PEOPLE WITH DISABILITIES 3, 22 (2011) (summarizing a national study, which revealed that “[o]nly 23 percent of doctors’ offices and hospitals offered patient information in large print, and only 24 percent offered patient information in an accessible format”).

³³ The doubled rates of dissatisfaction with the quality of health care received were 8.1-percent versus 4-percent, and inadequate information provided about their health conditions were 11-percent versus 6-percent. Bonnie L. O'Day et al., *Improving Health Care Experiences of Persons Who Are Blind or Have Low Vision: Suggestions from Focus Groups*, 19 AM. J. OF MED. QUALITY 193, 194 (2004).

³⁴ NYLPI has heard such concerns expressed by New Yorkers with disabilities through its intake line and at outreach and education events.

³⁵ See, e.g., Settlement Agreement Under the Americans with Disabilities Act Between the United States of America and Dr. Bruce Berenson, M.D., P.A. for Complaint USAO No: 2011-VO-0468/DJ No. 202-18-267, Aug. 1, 2012 [hereinafter “Berenson Settlement”], available at http://www.ada.gov/berenson_settle.htm (last visited Oct. 22, 2012) (addressing a complaint against a medical office for refusing to allow a patient with a disability to bring his service animal into the office).

³⁶ See, e.g., Rolanda L. Ward et al., *Uncovering Health Care Inequalities among Adults with Intellectual and Developmental Disabilities*, 35(4) HEALTH & SOCIAL WORK 280, 286 (2010).

³⁷ See Ward et al., *supra* note 36, at 285–87.

³⁸ Oliver Lord et al., *Receipt of preventive medical care and medical screening for patients with mental illness: a comparative analysis*, 32 GEN. HOSP. PSYCHIATRY 519, 539 (2010).

³⁹ Graham Thornicroft, *Physical health disparities and mental illness: the scandal of premature mortality*, 199 BRIT. J. OF PSYCHIATRY 441, 441 (2011).

⁴⁰ *Opinion 10.01 - Fundamental Elements of the Patient-Physician Relationship*, AM. MED. ASS'N, available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion1001.page> (last visited Oct. 22, 2012).

⁴¹ NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 49.

⁴² Silvia Yee, Staff Attorney, Disability Rights Education and Defense Fund, Disability Discrimination in Health Care, Presented at the Jacobus tenBroek Disability Law Symposium (April 2012), at 4, <http://dredf.org/healthcare/tenBroek-4-20-12.pdf>.

⁴³ NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 48 (citing Gloria L. Krahn & Charles E. Drumm, *Translating Policy Principles into Practice to Improve Health Care Access for Adults with Intellectual Disabilities: A Research Review of the Past Decade*, 13 MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES RES. REVIEWS 160–68 (2007)).

⁴⁴ T.J. Larsen et al., *Effective Communication with Deaf Patients and Awareness of the Americans with Disabilities Act Among Emergency Personnel: A National Study*, 34 ANNALS OF EMERGENCY MED. S24, S24 (1999).

⁴⁵ Michelle A. Larson McNeal et al., CTR. FOR DISABILITY ISSUES & THE HEALTH PROFESSIONS, PROVIDING PRIMARY HEALTH CARE FOR PEOPLE WITH PHYSICAL DISABILITIES: A SURVEY OF CALIFORNIA PHYSICIANS 8 (2002), <http://www.cdihp.org/pdf/ProvPrimeCare.pdf>.

⁴⁶ *Id.* at 11.

⁴⁷ *Id.*

⁴⁸ CODE OF MEDICAL ETHICS, *supra* note 13.

⁴⁹ 29 U.S.C. § 794(b)(3)(A)(ii) defines “program or activity” as “an entire corporation, partnership or other private organization, or an entire sole proprietorship, which is principally engaged in the business of providing . . . health care” *See also*, 45 C.F.R. Pt. 84, App. A, subpart a.2.

⁵⁰ *See* 42 U.S.C. § 12131(1)(A).

⁵¹ *See* 42 U.S.C. § 12181(7) (listing entities that constitute “public accommodations”); 28 C.F.R. § 36.104 (defining “place of public accommodation” and listing examples).

⁵² *See Rodal v. Anesthesia Grp. of Onondaga, P.C.*, 369 F.3d 113, n.1 (2d Cir. 2004) (“New York State disability discrimination claims are governed by the same legal standards as federal ADA claims.”).

⁵³ “Interpretations of New York state or federal statutes with similar wording may be used to aid in interpretation of New York City Human Rights Law, viewing similarly worded provisions of federal and state civil rights laws as a floor below which the City’s Human Rights law cannot fall, rather than a ceiling above which the local law cannot rise.” N.Y.C. Local Law 85, § 1 (Oct. 3, 2005).

⁵⁴ N.Y. EXEC. LAW § 292(9) (explicitly naming clinics and hospitals); Admin. Code of the City of New York § 8-102(9).

⁵⁵ *See* 42 U.S.C. § 12102 (ADA definition of “disability”); 29 U.S.C. § 705(20) (Rehab Act definition of “individual with a disability”); N.Y. EXEC. LAW § 292(21) (State Human Rights Law definition of “disability”); Admin. Code of the City of New York § 8-102(16) (City Human Rights Law definition of “disability”). The State and City Human Rights Laws define “disability” more expansively than federal laws. *See Treglia v. Town of Manlius*, 313 F.3d 713, 723 (2d Cir. 2002) (“New York and Second Circuit cases make clear that the New York disability statute defines disability more broadly than does the ADA.”).

⁵⁶ 42 U.S.C. §§ 12102(1)(B)-(C), 12102(3) (ADA, including within its definition of “disability” “a record of such an impairment” and “being regarded as having such an impairment”); 29 U.S.C. § 705(20)(B) (Rehab Act, incorporating the ADA’s definition of “disability”); N.Y. EXEC. LAW § 292(21) (including within its definition of “disability” “a record of such an impairment or . . . a condition regarded by others as such an impairment”); Admin. Code of the City of New York §§ 8-102(16), 8-107(4) (including within its definition of disability “a history or record of such impairment” and defining discrimination to include discrimination based on “actual or perceived” disability); 28 C.F.R. § 35.104 (ADA Title II regulation); 28 C.F.R. § 36.104 (ADA Title III regulation).

⁵⁷ 42 U.S.C. § 12203(a); N.Y. EXEC. LAW § 296(7); Admin. Code of the City of New York § 8-107(7).

⁵⁸ 42 U.S.C. §§ 12132, 12182(b)(1)(A) (ADA Title II and Title III, respectively); 29 U.S.C. § 794(a) (Rehab Act); N.Y. EXEC. LAW § 296(2)(a) (State Human Rights Law); Admin. Code of the City of New York § 8-107(4)(a) (City Human Rights Law); 28 C.F.R. §§ 35.130(a), 35.130(b)(1)-(2) (Title II regulations); 28 C.F.R. §§ 36.201(a) (Title III regulation).

⁵⁹ 42 U.S.C. § 12182(b)(2)(A)(iii)-(iv) (Title III); N.Y. EXEC. LAW §§ 296(2)(c)(iii)-(iv) (State Human Rights Law); Admin. Code of the City of New York § 8-102(18) (City Human Rights Law); 28 C.F.R. § 36.304 (Title III regulation). In addition, new construction at health care facilities must comply with the ADA Accessibility Guidelines for Buildings and Facilities (ADAAG), which contains scoping and technical requirements for accessibility to buildings and facilities. U.S. DEP’T OF JUSTICE, 2010 ADA STANDARDS FOR ACCESSIBLE DESIGN (2010), <http://www.ada.gov/regs2010/2010ADASTandards/2010ADASTandards.pdf>.

⁶⁰ 28 C.F.R. § 36.304(a)-(b) (Title III regulation requiring barrier removal and listing 21 examples of barrier removal).

⁶¹ *See* U.S. DEP’T OF JUSTICE, ACCESS TO MEDICAL CARE, *supra* note 22, at Part 4. Although medical providers are already obligated by federal, state and local law to ensure the accessibility of the health care services, the Patient Protection and Affordable Care Act of 2010 (PPACA) calls for even more detailed standards of accessible medical diagnostic equipment. *See* 42 U.S.C. § 18001 *et seq.* The PPACA amends 29 U.S.C. 791 *et seq.* (Title V of the Rehabilitation Act of 1973) by adding § 510(a)-(c), “Establishment of Standards for Accessible Medical Diagnostic Equipment,” which authorizes the United States Access Board to develop new access standards for medical diagnostic equipment including “examination tables and chairs, weight scales, x-ray machines and other radiological equipment, and mammography equipment.” Access Board to Set Standards for Medical Diagnostic Equipment under Health Care Reform Law, *available at* <http://www.access-board.gov/news/medical-equipment.htm> (last visited Oct. 22, 2012). Similarly, the Department of Justice is developing regulations for medical equipment and furniture. *See* Nondiscrimination on the Basis of Disability by State and Local Governments and Places of Public Accommodation; Equipment and Furniture, 175 Fed. Reg. 43,452 (July 26, 2010) (to be codified at 28 C.F.R. pts. 35 & 36) (comment submissions available at <http://www.regulations.gov/#!docketDetail;dt=FR+PR+N+O+SR+PS;rpp=10;po=0;D=DOJ-CRT-2010-0008>).

⁶² *See* U.S. DEP’T OF JUSTICE, AMERICANS WITH DISABILITIES ACT, ADA TITLE III TECHNICAL ASSISTANCE MANUAL COVERING PUBLIC ACCOMMODATIONS AND COMMERCIAL FACILITIES, III-7.8300 [hereinafter U.S. DEP’T OF JUSTICE, ADA TITLE III TECHNICAL ASSISTANCE MANUAL], *available at* <http://www.ada.gov/taman3.html> (last visited Oct. 22, 2012); U.S. DEP’T OF JUSTICE, ACCESS TO MEDICAL CARE, *supra* note 22, at Part 4.

⁶³ U.S. DEP’T OF JUSTICE, ACCESS TO MEDICAL CARE, *supra* note 22, at 11-15.

⁶⁴ *Id.* at 19.

⁶⁵ *Id.* at 4, 19.

⁶⁶ 42 U.S.C. § 12182(2)(A)(iii) (Title III); N.Y. EXEC. LAW §§ 296(2)(c)(ii) (State Human Rights Law); Admin. Code of the City of New York § 8-107(15) (City Human Rights Law); 28 C.F.R. § 35.160(b) (Title II regulation); 28 C.F.R. § 36.303 (Title III regulation).

⁶⁷ 42 U.S.C. § 12103(1) (ADA); N.Y. EXEC. LAW §§ 296(2)(d)(ii) (State Human Rights Law); 28 C.F.R. § 35.104 (Title II regulation); 28 C.F.R. § 36.303(b) (Title III regulation).

⁶⁸ N.Y. EXEC. LAW §§ 296(2)(d)(ii) (State Human Rights Law); 28 C.F.R. § 35.104; 28 C.F.R. § 36.303(b).

⁶⁹ 42 U.S.C. § 12182(b)(2)(A)(iii) (Title III); N.Y. EXEC. LAW §§ 296(2)(c)(ii) (State Human Rights Law); Admin. Code of the City of New York § 8-102(18) (City Human Rights Law); 28 C.F.R. § 35.164 (Title II regulation); 28 C.F.R. § 36.303(a) (Title III regulation).

⁷⁰ 28 C.F.R. § 35.160 (Title II regulation); 28 C.F.R. § 36.303(c)(1) (Title III regulation).

⁷¹ 28 C.F.R. § 35.160(c)(1) (Title II regulation); 28 CFR § 36.303(c)(2) (Title III regulation).

⁷² 28 C.F.R. § 35.130(f) (Title II regulation); 28 C.F.R. § 36.301(c) (Title III regulation).

⁷³ 42 U.S.C. § 12182(b)(2)(A)(ii) (Title III); 28 C.F.R. § 35.130(b)(7) (Title II regulation); 28 C.F.R. § 36.302 (Title III regulation).

⁷⁴ 28 C.F.R. § 35.136(a) (Title II regulation); 28 C.F.R. § 36.302(c)(1) (Title III regulation); *see also* U.S. DEP'T OF JUSTICE, ADA TITLE III TECHNICAL ASSISTANCE MANUAL, at III-4.2300, *supra* note 62.

⁷⁵ *See* U.S. DEP'T OF JUSTICE, ACCESS TO MEDICAL CARE, *supra* note 22, at 19.

⁷⁶ *See id.* at 16.

⁷⁷ Jock Hoffman, *Are You Ready?*, STRATEGIES FOR PATIENT SAFETY, ACADEMIC GRP. (April 2010), *available at* <http://www.academicins.com/articles/SPS-academic-4-2010.html> (last visited Oct. 22, 2012) (emphasis added).

⁷⁸ 42 U.S.C. § 794(c) (Rehab Act); 42 U.S.C. § 12133 (Title II, incorporating the enforcement provisions of the Rehab Act); 42 U.S.C. § 12188 (Title III); N.Y. EXEC. LAW § 297 (State Human Rights Law); Admin. Code of the City of New York §§ 8-109, 8-502 (City Human Rights Law); 28 C.F.R. § 35.170 (Title II regulation); 28 C.F.R. § 36.502 (Title III regulation). Note that medical providers might also be liable for negligence and/or medical malpractice in cases where they fail to provide safe, accessible care.

⁷⁹ *See* Settlement Agreement Between the United States of America and Medical Specialists of the Palm Beaches, Inc., Sept. 28, 2012 [hereinafter "Medical Specialists of the Palm Beaches Settlement"], *available at* <http://www.ada.gov/mspb-settlement.htm> (last visited Oct. 22, 2012) (requiring medical provider to provide an accessible scale, as well as training for staff on ADA requirements and transferring patients with disabilities to an examination or imaging table); Settlement Agreement Between the United States of America and Marin Magnetic Imaging, July 21, 2006, at ¶¶ 4, 9 [hereinafter "Marin Magnetic Imaging Settlement"], *available at* <http://www.ada.gov/marinmagim.htm> (last visited Oct. 22, 2012) (summarizing investigation in which U.S. DOJ determined that medical office failed to reasonably accommodate a patient with a disability by "not providing him the equipment and/or assistance he needed to get onto the exam table, in violation of Title III of the ADA" and requiring that the medical office pay \$2000 to the patient); Settlement Agreement Between the United States of America and Valley Radiologists Medical Group, Inc., Nov. 2, 2005, at ¶ 4 [hereinafter "Valley Radiologists Settlement"], *available at* <http://www.ada.gov/vri.htm> (last visited Oct. 22, 2012) (summarizing investigation in which U.S. DOJ determined that medical office failed to reasonably accommodate a patient with a disability by "not providing her the assistance she needed to get onto the examination table, in violation of Title III of the ADA"); Settlement Agreement Between the United States of America and Exodus Women's Center, Inc., Apr. 26, 2005, at ¶ 4 [hereinafter "Exodus Settlement"], *available at* <http://www.ada.gov/exodus.htm> (last visited Oct. 22, 2012) (same); Settlement Agreement Between the United States of America and Dr. Robila Ashfaq, Jan. 10, 2005, at ¶ 4 [hereinafter "Ashfaq Settlement"], *available at* <http://www.ada.gov/drashfaq.htm> (last visited Oct. 22, 2012) (same); *see also* Settlement Agreement Among the United States of America, Plaintiffs Equal Rights Center, Dennis Christopher Butler, Rosemary Ciotti, George Aguehounde, and Marsha Johnson, and Washington Hospital Center, Nov. 1, 2005 [hereinafter "Washington Hospital Settlement"], *available at* www.ada.gov/whc.htm (last visited Oct. 22, 2012) (requiring hospital to implement extensive changes in policies, practices, and medical equipment). Private settlement agreements have also been reached in actions involving inaccessible medical facilities across the country. *See, e.g.*, Settlement Agreement: Metzler et al. v. Kaiser Foundation Health Plan, Inc. et al., March 2001, *available at* <http://www.dralegal.org/downloads/cases/metzler/settlement.pdf> (last visited Oct. 22, 2012); Settlement Agreement Between UCSF Medical Center and August Longo, *available at* <http://llegal.com/2008/09/ucsf-settlement-agreement/> (last visited Oct. 22, 2012). Information regarding other medical access settlement agreements can be found on The Barrier Free Health Care Initiative's website at http://thebarrierfreehealthcareinitiative.org/?page_id=16 (last visited Oct. 22, 2012).

⁸⁰ *See, e.g.*, Settlement Agreement Between the United States of America and Northshore University Health Systems, June 25, 2012 [hereinafter "NorthShore Settlement"], *available at* <http://www.ada.gov/northshore-uni-sa.htm> (last visited Oct. 22,

2012) (requiring hospital to pay \$46,990.00 to complainants' heir for hospital's failure to provide sign language interpreters on three occasions). A medical provider's failure to provide for effective communication could result in the failure to obtain informed consent from a patient, effectively understand and diagnose a patient's medical condition, or properly explain treatment or medications. *See id.* at ¶ 30 (listing examples of circumstances in which the length or complexity of the communication warrants provision of a sign language interpreter).

⁸¹ *See, e.g.*, Berenson Settlement, *supra* note 35, at ¶ 3 (summarizing investigation in which U.S. DOJ determined that a medical office effectively denied a person with a disability access to medical services in violation of the ADA when it "inappropriately questioned and objected to the presence of the complainant's service animal in the office's waiting area").

⁸² N.Y. EXEC. LAW §§ 297(4)(c), 297(9) (State Human Rights Law); Admin. Code of the City of New York §§ 8-120, 8-502 (City Human Rights Law),

⁸³ *See* 42 U.S.C. § 12188(b)(2)(B) (Title III); *see e.g.*, NorthShore Settlement, *supra* note 80, at ¶ 48. *See also* N.Y. EXEC. LAW §§ 297(4)(c), 297(9) (State Human Rights Law); Admin. Code of the City of New York §§ 8-120, 8-502 (City Human Rights Law); Mary Pat Gallagher, *Jury Awards \$400,000 to Deaf Patient for Denial of Interpreter Services*, N.J. L. J., Oct. 17, 2008, available at http://www.law.com/jsp/article.jsp?id=1202425326286&Jury_Awards_400000_to_Deaf_Patient_for_Denial_of_Interpreter_Services&slreturn=20120916114420 (last visited Oct. 22, 2012).

⁸⁴ *See* 42 U.S.C. § 12188(a)(2) (Title III). "[I]njunctive relief shall include an order to alter facilities to make such facilities readily accessible to and usable by individuals with disabilities to the extent required by this subchapter. Where appropriate, injunctive relief shall also include requiring the provision of an auxiliary aid or service, modification of a policy, or provision of alternative methods, to the extent required by this subchapter." *Id.*; *see also* N.Y. EXEC. LAW §§ 297(4)(c), 297(9) (State Human Rights Law); Admin. Code of the City of New York §§ 8-120, 8-502 (City Human Rights Law). *See also, e.g.*, Medical Specialists of the Palm Beaches Settlement, *supra* note 79; Berenson Settlement, *supra* note 35; Northshore Settlement, *supra* note 80; Marin Magnetic Imaging Settlement, *supra* note 79; Ashfaq Settlement, *supra* note 79; Washington Hospital Settlement, *supra* note 79; Valley Radiologists Settlement, *supra* note 79; Exodus Settlement, *supra* note 79.

⁸⁵ 42 U.S.C. § 12205 (ADA); 42 U.S.C. § 794a(b) (Rehab Act); Admin. Code of the City of New York, § 8-502(f) (City Human Rights Law).

⁸⁶ 42 U.S.C. § 12188(b)(2)(C) (Title III provision, that a court "may, to vindicate the public interest, assess a civil penalty against the entity in an amount (i) not exceeding \$50,000 for a first violation; and (ii) not exceeding \$100,000 for any subsequent violation"); N.Y. EXEC. LAW § 297(9) (providing for assessment of "civil fines and penalties in an amount not to exceed fifty thousand dollars, to be paid to the state by a respondent found to have committed an unlawful discriminatory act, or not to exceed one hundred thousand dollars to be paid to the state by a respondent found to have committed an unlawful discriminatory act which is found to be willful, wanton or malicious"); Admin. Code of the City of New York, § 8-404 (providing that "the trier of fact may, to vindicate the public interest, impose upon any person who is found to have engaged in a pattern or practice that results in the denial to any person of the full enjoyment of any right secured by chapter one of this title a civil penalty of not more than two hundred fifty thousand dollars").

⁸⁷ U.S. DEP'T OF HEALTH & HUMAN SERV., NAT'L INST. FOR OCCUPATIONAL SAFETY & HEALTH, AND CTRS. FOR DISEASE CONTROL & PREVENTION, SAFE HANDLING TRAINING FOR STUDENTS OF NURSING: CURRICULAR MATERIALS 6 (2009), <http://www.cdc.gov/niosh/docs/2009-127/pdfs/2009-127.pdf> [hereinafter HHS, SAFE HANDLING TRAINING FOR STUDENTS OF NURSING] (citing AUDREY L. NELSON ET AL., THE ILLUSTRATED GUIDE TO SAFE PATIENT HANDLING AND MOVEMENT (2009), <http://www.mtpinnacle.com/pdfs/Guide-to-Safe-Patient-Handling.pdf>); STAFF OF SUBCOMM. ON WORKPLACE SAFETY, SUBCOMM. ON LABOR, SUBCOMM. ON HEALTH, N.Y. STATE ASSEMBLY, SAFE PATIENT HANDLING IN NEW YORK: SHORT TERM COSTS YIELD LONG-TERM RESULTS 6 (Comm. Print 2011) [hereinafter SAFE PATIENT HANDLING IN NEW YORK]; MARTIN H. COHEN ET AL., FACILITY GUIDELINES INST., PATIENT HANDLING AND MOVEMENT ASSESSMENTS: A WHITE PAPER 18, 21-22 (Carla M. Borden, ed., 2010), http://www.dli.mn.gov/WSC/PDF/FGI_PHAMAwhitepaper_042710.pdf.

⁸⁸ SAFE PATIENT HANDLING IN NEW YORK, *supra* note 87, at 6; COHEN ET AL., *supra* note 87, at 21.

⁸⁹ SAFE PATIENT HANDLING IN NEW YORK, *supra* note 87, at 6.

⁹⁰ COHEN, ET AL., *supra* note 87, at 24 (citing A. B. de Castro, *Handle with care: The American Nurses Association's Campaign to address work-related musculoskeletal disorders*, 9(3) ONLINE J. OF ISSUES IN NURSING, 103 (2004)).

⁹¹ JUNE ISAACSON KAILES ET AL., CTR. FOR DISABILITIES ISSUES & THE HEALTH PROFESSIONS, IMPORTANCE OF ACCESSIBLE EXAMINATION TABLES, CHAIRS AND WEIGHT SCALES 3 (2010).

⁹² See Cohen et al., *supra* note 86, at 24 (citing J. W. Collins et al., *An evaluation of a 'best practices' musculoskeletal injury prevention program in nursing homes*, 10 INJURY PREVENTION 206 (2004); Bradley A. Evanoff et al., *Reduction in injury rates in nursing personnel through introduction of mechanical lifts in the workplace*, 44 AM. J. OF INDUS. MED. 451 (2003); Hester J. Libscomb et al., *Evaluation of direct workers' compensation costs for musculoskeletal injuries surrounding interventions to reduce patient lifting*, 69 OCCUPATIONAL & ENVTL. MED. 367 (2012); Audrey Nelson, et al., *Development and Evaluation of a Multifaceted Ergonomics Program to Prevent Injuries Associated with Patient Handling Tasks*, 43 INT'L J. OF NURSING STUDIES 717 (2006); A. Nelson & A. Baptiste, *Evidence-based practices for safe patient handling and movement*, 9 ONLINE J. OF ISSUES IN NURSING 3 (2004), http://asphp.org/wp-content/uploads/2011/05/Audrey_Nelson_Paper_on_Safe_Patient_Handling.pdf).

⁹³ SAFE PATIENT HANDLING IN NEW YORK, *supra* note 87, at 7 (“In nine National Institute of Occupational Safety and Health case studies, there were: 60-95-percent reduction in injuries; 95-percent reduction in workers’ compensation costs; 92-percent reduction in medical/indemnity costs; as much as 100-percent reduction in lost work days (absence due to injury); 98-percent reduction in absenteeism (absence due to unreported injury).”). See also, HHS, SAFE HANDLING TRAINING FOR STUDENTS OF NURSING, *supra* note 87, at 6; Cohen et al., *supra* note 87, at 43 (citing Collins et al., *supra* note 92; Evanoff et al., *supra* note 92; Nelson et al., *supra* note 92; Nelson & Baptiste, *supra* note 92).

⁹⁴ U.S. DEP’T OF JUSTICE, TAX INCENTIVES FOR BUSINESSES [hereinafter U.S. DEP’T OF JUSTICE, TAX INCENTIVES FOR BUSINESSES], available at <http://www.ada.gov/taxinent.htm> (last visited Oct. 19, 2012) (“Small businesses with 30 or fewer employees or total revenues of \$1 million or less can use the Disabled Access Credit.”). See also I.R.C. § 44 (2006).

⁹⁵ U.S. DEP’T OF JUSTICE, TAX INCENTIVES FOR BUSINESSES, *supra* note 94 (“Eligible small businesses may take a credit of up to \$5,000 (half of eligible expenses up to \$10,250, with no credit for the first \$250).”).

⁹⁶ *Id.* (eligible businesses can use the credit “to offset their costs for access, including barrier removal from their facilities (e.g., widening a doorway, installing a ramp), provision of accessibility services (e.g., sign language interpreters), provision of printed material in alternate formats (e.g., large-print, audio, Braille), and provision or modification of equipment.”).

⁹⁷ *Id.* (“Under Internal Revenue Code, Section 190, businesses can take a business expense deduction of up to \$15,000 per year for costs of removing barriers in facilities or vehicles.”). See also I.R.C § 190 (2006). Neither the tax credit, nor the deduction may be applied to the cost of new construction and all barrier removal must comply with federal accessibility standards. U.S. DEP’T OF JUSTICE, TAX INCENTIVES FOR BUSINESSES, *supra* note 97.

⁹⁸ See ME Caban, MD et al., *Mammography Use May Partially Mediate Disparities in Tumor Size at Diagnosis in Women with Social Security Disabilities*, 46(4) WOMEN AND HEALTH 1, 7 (2007).

⁹⁹ Martijn T. Groot et al., *Costs and Health Effects of Breast Cancer Interventions in Epidemiologically Different Regions of Africa, North America, and Asia*, 12 THE BREAST J. S81, S88 (2006), http://www.who.int/choice/publications/p_2006_breast_cancer.pdf.

¹⁰⁰ See Paul T. Cheung et al., *National Study of Barriers to Timely Primary Care and Emergency Department Utilization Among Medicaid Beneficiaries*, 60(1) Annals of Emergency Med. 4, 4, 7 (2012) (national study of the association between five barriers to primary care, such as limited clinic hours and lack of transportation, and emergency department usage for Medicaid and private insurance beneficiaries). This study by Cheung, et al. found that Medicaid recipients experienced more barriers to primary care than privately insured patients, and were more likely to use the emergency department. *Id.* Other barriers to primary care such as inaccessible medical offices or equipment may likewise increase emergency department usage for people with disabilities. See also, DISABLED WORLD, EMERGENCY DEP’T USE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, *First North American study to look at ED use by adults with intellectual disabilities* (May 15, 2011), available at <http://www.disabled-world.com/medical/rehabilitation/emergency-department.php#ixzz29J1QX5GE> (last visited Oct. 22, 2012).

¹⁰¹ See U.S. GOV’T ACCOUNTABILITY OFF., GAO-11-414R, HOSPITAL EMERGENCY DEPARTMENTS: HEALTH CENTER STRATEGIES THAT MAY HELP REDUCE THEIR USE 2 (2011), <http://www.gao.gov/assets/130/126188.pdf> (reporting the significantly higher cost of emergency department visits as compared to health center visits).

¹⁰²

According to estimates from the 2008 Medical Expenditures Panel Survey (MEPS), the average amount paid for a nonemergency visit to an emergency department was \$792, while the average amount paid for a health center visit was \$108. Similarly, the average charge for a nonemergency visit to an emergency department was 10 times higher than the charge for a visit to a health center—\$2,101 compared to \$203. MEPS is a set of large-scale surveys of families and individuals, their medical providers, and their employers across the United States.

Id. at n.5.

¹⁰³ Women with disabilities are significantly less likely to have a doctor recommend they receive a pap smear. Anthony Ramirez et al., *Disability and Preventive Cancer Screening: Results from the 2001 California Health Interview Survey*, 95(11) AM. J. OF PUB. HEALTH 2057, 2061 (2005). Relatedly, several studies have shown that medical providers frequently wrongly assume that women with disabilities are not sexually active. NAT’L COUNCIL ON DISABILITY, *supra* note 1, at 55-56.

¹⁰⁴ U.S. CENSUS BUREAU, *supra* note 5, at tbl.B18101.

¹⁰⁵ McCarthy et al., *supra* note 3, at 637 (cited in JUNE ISAACSON KAILES ET AL., CTR. FOR DISABILITY ISSUES & THE HEALTH PROFESSIONS, MAMMOGRAPHY: ADDRESSING EQUIPMENT DESIGN 5 (2009)).

Women with SSDI and Medicare who had breast-conserving surgery were also less likely than other women to receive radiotherapy and axillary lymph node dissection. These women had lower survival rates from all causes and specifically from breast cancer. Explanations for such disparities could include lack of early diagnosis, lack of breast health awareness or education on the part of the woman herself, inaccessible or unreliable transportation, and cultural capacity of the treating facility. Inaccessible equipment and other physical barriers could also add to the problem.

Id.

¹⁰⁶ Lisa I. Iezzoni et al., *Mobility Impairments and Use and of Screening and Preventative Services*, 90(6) AM. J. OF PUB. HEALTH. 955, 957 (2000), <http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.90.6.955>.

¹⁰⁷ Siran M. Koroukian et al., *Mental Illness and Use of Screening Mammography Among Medicaid Beneficiaries*, 42(6) AM. J. OF PREVENTATIVE MED. 606, 608 (2012).

¹⁰⁸ Joanne E. Wilkinson et al., *'It's Easier Said Than Done': Perspectives on Mammography from Women with Intellectual Disabilities*, 9 ANNALS OF FAMILY MED. 142, 143 (2011) (citing N. Davies & M. Duff, *Breast cancer screening for older women with intellectual disabilities living in community group homes*, 45 J. INTELLECTUAL DISABILITY RES. 253 (2001)).

¹⁰⁹ Joann M. Thierry, *Observations from the CDC: Increasing Breast and Cervical Cancer Screening among Women with Disabilities*, 9(1) J. OF WOMEN'S HEALTH & GENDER-BASED MED. 9, 9 (2000) (citing Centers for Disease Control and Prevention, *National breast and cervical early detection program*, 45 MMWR. 484 (1999)).

¹¹⁰ INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT FOR WOMEN WITH PHYSICAL DISABILITIES: A REPORT ON PRELIMINARY FINDINGS, APRIL 1, 2008 – MARCH 31, 2010. 2 (2011), http://www.icsny.org/sitemanagement/wp-content/uploads/2011/03/FINAL-KOMEN_report.pdf [hereinafter INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT]. ICS was also a recipient of the Susan G. Komen Grantee of the Year Award in 2012.

¹¹¹ Many frequently used mammography machines are inaccessible to women with physical disabilities. See INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT, *supra* note 110, at 5.

¹¹² Depending on the severity of the disability, ICS found in its project that between 12%-42% of women with disabilities needed an additional technologist to receive a mammogram, and the time required for the test ranged from 19 to 33 minutes. INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT, *supra* note 110, at 3; Independence Care System, Final Report, *supra* note 12, at App. A-1. See also Iezzoni, et al., *Physical Access to Diagnosis and Treatment of Breast Cancer*, *supra* note 20, at 714.

¹¹³ Telephone Interview with Jane D. Nietes, Nurse Educator, Independence Care System (Oct. 9, 2012) [hereinafter Telephone Interview with Jane D. Nietes (Oct. 9, 2012)].

¹¹⁴ Telephone Interview with Jane D. Nietes (Oct. 9, 2012), *supra* note 113.

¹¹⁵ Telephone Interview, Member, Independence Care System (Oct. 4, 2012) [hereinafter Independence Care System Member Interview].

¹¹⁶ NAT'L COUNCIL ON DISABILITY, *supra* note 1, at 58-59.

¹¹⁷ Telephone Interview with Jane D. Nietes (Oct. 9, 2012), *supra* note 113.

¹¹⁸ Telephone Interview with Jane D. Nietes (Oct. 9, 2012), *supra* note 113; Telephone Interview with Jane D. Nietes, Nurse Educator, Independence Care System (Oct. 21, 2012) [hereinafter Telephone Interview with Jane D. Nietes (Oct. 21, 2012)].

¹¹⁹ INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT, *supra* note 110, at 4; see also Telephone Interview with Jane D. Nietes (Oct. 9, 2012), *supra* note 113.

¹²⁰ INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT, *supra* note 110, at 4.

¹²¹ Telephone Interview with Jane D. Nietes (Oct. 9, 2012), *supra* note 113.

¹²² Telephone Interview with Jane D. Nietes (Oct. 21, 2012), *supra* note 118.

¹²³ Telephone Interview with Jane D. Nietes (Oct. 9, 2012), *supra* note 113; Telephone Interview with Jane D. Nietes (Oct. 21, 2012), *supra* note 118.

¹²⁴ Telephone Interview with Jane D. Nietes (Oct. 21, 2012), *supra* note 118.

¹²⁵ *Id.*

¹²⁶ Telephone Interview with Jane D. Nietes (Oct. 9, 2012), *supra* note 113.

¹²⁷ Independence Care System Member Interview, *supra* note 115.

¹²⁸ INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT, *supra* note 110, at App. B-2.

¹²⁹ Telephone Interview with Jane D. Nietes (Oct. 21, 2012), *supra* note 118.

¹³⁰ Independence Care System, Final Report, *supra* note 12, at App. A-2.

¹³¹ INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT, *supra* note 110, at 5.

¹³² See 42 U.S.C. § 290ii; 42 C.F.R. § 482.13(e); N.Y. COMP. CODES R. & REGS. TIT. 10 § 405.7(5).

¹³³ 42 U.S.C. § 290ii(d)(1)(A) defines restraints as “any physical restraint that is a mechanical or personal restriction that immobilizes or reduces the ability of an individual to move his or her arms, legs, or head freely, *not including devices*, such as orthopedically prescribed devices, surgical dressings or bandages, protective helmets, *or any other methods that involves the physical holding of a resident for the purpose of conducting routine physical examinations or tests* or to protect the resident from falling out of bed or to permit the resident to participate in activities without the risk of physical harm to the resident.” (emphasis added). 42 C.F.R. § 482.13(e)(1)(i)(C) states that: “[a] restraint does not include devices, such as orthopedically prescribed devices, surgical dressings or bandages, protective helmets, *or other methods that involve the physical holding of a patient for the purpose of conducting routine physical examinations or tests*, or to protect the patient from falling out of bed, or to permit the patient to participate in activities without the risk of physical harm” (emphasis added). 10 NYCRR § 405.7(b)(5) limits the use of restraints “to those patient restraints authorized in writing by a physician after a personal examination of the patient, for a specified and limited period of time to protect the patient from injury to himself or to others.”

¹³⁴ INDEPENDENCE CARE SYSTEM, BREAST CANCER SCREENING PROJECT, *supra* note 110, at 4.
