



***Access to Healthcare for
Women & Girls with Disabilities***

A Report to Pennsylvania's Legislators



July 2012

[The U.S. Department of Health and Human Services] HHS has provided guidance to states on implementation and enforcement of the ADA and Section 504 but has not established any mechanisms for monitoring states' actions. Funding is not tied to any requirement that states report on progress to ensure compliance by health care providers.¹ This weakness in Federal health care oversight for people with disabilities has received little public attention and does not appear to be a priority of any Federal agency that has a substantial role in researching, assessing, or directly providing health care for people with disabilities.² For some people with disabilities, the twin dimensions of health care access—adequate insurance coverage and benefits, and health care facility and programmatic accessibility—are inextricably entwined. Yet Federal agencies involved with health care for people with disabilities have not acted affirmatively to elevate attention to, and spur action on, the architectural and programmatic elements.³

The Current State of Health Care for People with Disabilities
National Council on Disability September 30, 2009

¹ National Council on Disability, *The Current State of Health Care for People with Disabilities, Report to the President and Congress*, (2009), cited *Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs*, Department of Health and Human Services, Health Care Financing Administration, Center for Medicaid State Operations, Baltimore, MD, October 1998.

²Ibid. cited "Medi-Cal Health Plan Readiness Assessment Tool," released in 2008, reflects the recommendations of the 2005 California Health Care Foundation report and helps determine whether a plan is prepared to enroll and serve additional beneficiaries with disabilities. See www.chcf.org/topics/medi-cal/index.cfm?itemID=113558 (accessed September 9, 2008)

³ Ibid.

Access to Healthcare for Women and Girls with Disabilities - Executive Summary

The Problem

Women and girls with disabilities have difficulty getting basic medical care. Twenty years after the Americans with Disabilities Act (ADA), many medical provider offices are still not accessible for women with mobility, communication and sensory disabilities. When access to healthcare is denied, not only are people at risk of serious health consequences, but hospitals and medical providers are at risk of exposure to federal lawsuits.

Pennsylvania's women with disabilities are likely:

- not weighed routinely for medications (mobility)
- unable to identify what prescription they are taking - they need Braille or audible prescription bottles.⁴ (vision)
- not provided an interpreter or captioner in a private health care conversation (hearing)
- unable to know what forms they are signing (vision; intellectual disability)
- unable to access all medical providers buildings, treatment rooms, exam tables and diagnostic testing equipment (mobility)
- unable to find a provider with the education and experience to treat them (all)

Solutions

When women with disabilities are able to access routine healthcare, they have fewer hospitalizations and fewer emergency room visits, reducing overall costs for both public and private payers.

1. Enact legislation to educate and monitor and enforce accessibility requirements through the Americans with Disabilities Act (ADA) for all medical providers.
2. Integrate ADA requirements into Department of Health licensing requirements for health care professionals and facilities.
3. Enact legislation that requires private health insurers to reimburse providers for the cost of interpreters, captioners, Braille and other ADA required accommodations.
4. Ensure that Pennsylvania's women with disabilities are able to receive a mammogram and other preventative diagnostic tests and imaging.
5. Ensure that Pennsylvania's Medicaid (Medical Assistance) providers are compensated for the additional time and/or staff they may need to adequately meet the needs of their patients with disabilities.
6. Institute a more flexible (part time) medical and dental education loan repayment program, **using existing funds**, to incentivize health care professionals to serve people with disabilities and other Medicaid recipients, especially in Pennsylvania's underserved areas.
7. Expand the number of Medical Homes in Pennsylvania for adults with disabilities.

⁴The Equal Rights Center (2011), *Ill-Prepared: Health Care's Barriers for People with Disabilities*, "Audible bottles" are prescription bottles that have a device affixed to them that provide information regarding the medication audibly [by sound/speaking] to assist individuals with disabilities.

About ACHIEVA

ACHIEVA is Western Pennsylvania's largest provider of comprehensive services and supports for people with disabilities and their families. Each year, ACHIEVA serves more than 12,600 individuals with disabilities and their families and is the only agency of its type in western Pennsylvania that provides lifelong supports. From early intervention therapies to in-home support for medically fragile senior citizens, ACHIEVA provides a full spectrum of services for people of all ages and abilities and their families.

ACHIEVA's Disability Healthcare Initiative is providing statewide leadership on improving access to healthcare for individuals with disabilities through education and advocacy. We coordinate policy work to solve systemic issues by promoting short term strategies to increase physical and programmatic access as well as longer term approaches such as addressing medical workforce development and education.

ACHIEVA works with many stakeholders, including individuals with disabilities and their families, medical professionals, hospitals and health centers, government agencies, educators, insurance companies, foundations and disability advocates to develop viable solutions to increase access to health and dental care for people with disabilities.

In January 2010, ACHIEVA's Disability Healthcare Initiative committed to continuing the nationally recognized work of the FISA Foundation on increasing access to healthcare for women with disabilities. The basis for this work was built upon two-state wide forums: October 6, 2010 in Pittsburgh and March 7, 2011 in Hershey, Pennsylvania. These gatherings brought together women with disabilities and their families, medical professionals, hospital administrators, government leaders, educators, representatives from insurance companies and foundations, policymakers and disability advocates. We heard from state and national experts: self advocates, medical professionals, policymakers and hospital administrators who discussed viable solutions to increase access to healthcare for women and girls with disabilities in Pennsylvania. Both sessions were designed to identify key strategies and solutions, including:

- Developing a central website for Pennsylvanians – advocates, health care professionals, individuals with disabilities and policymakers – to learn more about the issues and to access a broad range of existing tools and resources.
- Developing a series of webinars and other media focused on access to healthcare.
- Educating key policymakers about specific barriers to healthcare for women with disabilities.

The Research

Women and girls with disabilities should be able to receive quality preventative health care from their medical providers. This requires that their health care is both accessible and respectful.

According to 2010 US Census figures⁵, 10 % of women in Pennsylvania ages 16 to 64 have disabilities. That number grows to 23% for women ages 65 to 74 and to just over 50% for women over the age of 75. Thanks to modern medical supports and technology, people with intellectual, developmental and physical disabilities are living longer. **The need for accessible health care is growing: people in general are living longer and acquiring disabilities as they age.**

The Pennsylvania Department of Aging reports that, “Pennsylvania’s population age 65 and over is expected to increase from 15% of the total population in 2010 to 19% in 2020, and 23% in 2030.”⁶ The likelihood of disability for everyone goes up significantly as we age: it shifts from “less than 10% for people 15 years of age or younger, to almost 75% for people 80 or older.”⁷

More Pennsylvania women will need accessibility accommodations in order to receive appropriate health care and long term care.

In a study using a national sample of low-income women who rely on Medicaid for their health care, researchers at the University of North Carolina looked at the contrasts between the health care access of women with and without disabilities. They concluded that, “Women with disabilities are more likely to develop secondary conditions if their needs are not met, yet they postpone needed care and medication at vastly higher rates than non disabled women.”⁸ **The cost of limited or non-existent access to healthcare is significant for these women and to the healthcare system.**

⁵US Census Bureau, *American Factfinder Results* (2010 American Community Survey-1year Estimates), sex by age by disability status
http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_1YR_B18101&prodType=table accessed 1 February 2012

⁶ Pennsylvania Department of Aging website (2012), Pennsylvania State Data Center,
<http://www.portal.state.pa.us/portal/server.pt?open=514&objID=616669&mode=2>, accessed 24 April 2012

⁷ U.S. Department of Health and Human Services. *The 2005 Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities: Calling You to Action*. U.S. Department of Health and Human Services, Office of the Surgeon General, 2005.

⁸ University of North Carolina Parish & Ellison-Martin 2007, <http://ssw.unc.edu/RTI/presentation/PDFs/Health-CareAccessofWomenMedicaidRecipients.pdf> accessed 12 November 2011 copyright 2007, Parish & Ellison-Martin (permission granted).

According to the Centers for Disease Control and Prevention⁹, 71.2% of women between the ages of 40-49 years of age and who do not have disabilities have had a mammogram. This percentage drops to 64.6% among women with disabilities. Breast cancer is the most common cancer in women. Due in part to inaccessible offices, mammography equipment that doesn't accommodate women who cannot stand independently, limited accessible transportation, and medical staff who are not well trained and feel ill at ease interacting with women who have complex disabilities, women with disabilities are missing out on life-saving diagnosis and treatment.

Research from the Centers for Disease Control has shown that “a substantially lower percentage of persons with disabilities than those without disabilities report their health to be excellent or very good (28.4% versus 61.4%).”¹⁰ While people with disabilities are “at risk for the same ailments and conditions as people in the general population (for example, injury, obesity, hypertension and the common cold), persons with disabilities also are at specific risk for secondary conditions that can damage their health status and the quality of their lives.”¹¹

Why Is Disability and Health Important?

The largest set of U.S. health data for people with disabilities, DATA2010, measures health at the population level.² These data highlight improvements in health over the previous decade and clearly reveal specific health disparities for people with disabilities. Compared with people without disabilities, people with disabilities are more likely to:

- Experience difficulties or delays in getting the health care they need.
- Not have had an annual dental visit.
- Not have had a mammogram in past 2 years.
- Not have had a Pap test within the past 3 years.
- Not engage in fitness activities.
- Use tobacco.
- Be overweight or obese.
- Have high blood pressure.
- Experience symptoms of psychological distress.
- Receive less social-emotional support.
- Have lower employment rates¹².

⁹ Centers for Disease Control and Prevention website (2012) <http://www.cdc.gov/Features/dsMammograms/>, accessed 24 April 2012.

¹⁰U.S. Department of Health and Human Services website (2012), Office on Disability Access To Quality Health Services And Disability - A Companion To Chapter 1 Of Healthy People 2010, accessed at http://www.hhs.gov/od/about/fact_sheets/healthypeople2010.html 1February 2012

¹¹U.S. Department of Health and Human Services website, Office on Disability (2012), Health, Wellness and Disability, accessed at http://www.hhs.gov/od/about/fact_sheets/healthwellnessdisability.html accessed February1, 2012

¹² Healthy People 2020 accessed at <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=9>
Cited ² Centers for Disease Control and Prevention (CDC), National Center for Health Statistics. DATA 2010 [Internet database]. Hyattsville, MD: CDC; 2010 [cited 2010 Sep 30]. Available from: <http://wonder.cdc.gov/data2010/focus.htm>

Barriers to Healthcare Access for Women and Girls with Disabilities

Women with disabilities experience barriers to access at multiple points of the healthcare process:

- How can prescriptions be given *if there is no knowledge* of how much someone weighs?
- How can a woman who is blind or has a visual disability know *what prescriptions she is taking without Braille labeling or audible bottles*¹³?
- How likely is it that a woman who is deaf has her privacy rights protected under the Health Insurance Portability and Accountability Act (HIPAA) *if she can't get an interpreter* who is adequately trained and licensed and who isn't a family member?
- How does a person with a visual disability sign forms at the hospital, if those forms are not made available in an accessible format (i.e., Braille, large print)
- How can a woman who uses a wheelchair have a successful examination if she cannot *get into the exam room and have sufficient clear floor space to transfer herself to the table?* How can that woman transfer herself to an exam table that does not lower sufficiently?
- Will a provider treat a woman with autism or an intellectual disability **if he or she has no experience serving people with these disabilities?**

I. Lack of Accessible Equipment

Women and girls with disabilities encounter extraordinary barriers accessing gynecologic care. *There is an extraordinary shortage of accessible medical equipment in gynecological settings.* Aside from the lack of accessible exam tables and scales, older mammography equipment may not have the capacity to move down and support a woman who uses a wheelchair. This can lead to uncomfortable positioning and an insulting experience for women trying to obtain a mammogram. The Americans with Disabilities Act (ADA) establishes federal standards for physical accessibility. In addition to office access, ADA protections also require that staff should be properly trained in wheelchair transfer, provide lift/transfer equipment and/or an accessible lift or chair.

Unfortunately, despite the ADA requirements, a substantial number of health care provider offices in Pennsylvania are still inaccessible. They may be located in older buildings with steps and no ramp, or the doors and hallways may be too narrow for someone using a large wheelchair to navigate. Equipment such as adjustable exam tables, scales and mammography machines may not be available. For women in rural areas of Pennsylvania, finding a physician with an accessible office is even more challenging.

Even more unfortunately, Pennsylvania has no existing system to ensure accessibility compliance. **In order to make a doctor's office accessible, someone with a disability has to sue the doctor, either by filing a complaint with the US Department of Justice, or filing in Federal Court. With few doctors willing to see people with disabilities in the first place, individuals with disabilities are unlikely to complain, much less file a lawsuit and they simply remain frustrated. They even elect to avoid preventative care altogether.**

The Patient Protection and Affordable Care Act signed into law on March 23, 2010 includes authorizing the United States Access Board to develop new standards for medical diagnostic equipment that will include exam tables, chairs, weight scales, x-ray machines and other radiological equipment and mammography equipment.¹³

As part of implementing the Affordable Care Act, once these equipment standards have been enacted, Pennsylvania will need to prepare for this change and to positively and proactively move forward by educating all medical professionals. Federal tax credits have been available and will continue to be available to providers who make efforts to remove barriers in their offices.

II. Lack of Accessible Health Communications

The ADA requires the doctor or dentist to provide reasonable accommodations at their cost (not that of the person or family) for a patient who needs accessible communications such as a qualified interpreter, Braille, large print, or recorded information. This cost is to be absorbed by the doctor; private and public insurances do not cover this as an expense. However, both data and personal testimonies suggest that this ADA requirement is widely ignored.

I need the doctor or the technician to look at me when he/she talks to me. He can't be writing or looking the other way when he/she is speaking to me. If he/she has a foreign accent, then I need him/her to write it down or ask the nurse to tell me or write down what he/she said. If the doctor wants to make sure that I understood the instructions correctly, they should be written down or typed and given to me. When I had my operations in the past, the staff always removed the masks from their face when he/she spoke to me.

-Arlene Miller, Pittsburgh

¹³ United States Access Board press release (2010), <http://www.access-board.gov/news/medical-equipment.htm>
SEC. 510. ESTABLISHMENT OF STANDARDS FOR ACCESSIBLE MEDICAL DIAGNOSTIC EQUIPMENT“
(a) STANDARDS.—Not later than 24 months after the date of enactment of the Affordable Health Choices Act, the Architectural and Transportation Barriers Compliance Board shall, in consultation with the Commissioner of the Food and Drug Administration, promulgate regulatory standards in accordance with the Administrative Procedure Act (2 U.S.C. 551 et seq.) setting forth the minimum technical criteria for medical diagnostic equipment used in (or in conjunction with) physician's offices, clinics, emergency rooms, hospitals, and other medical settings. The standards shall ensure that such equipment is accessible to, and usable by, individuals with accessibility needs, and shall allow independent entry to, use of, and exit from the equipment by such individuals to the maximum extent possible.
“(b) MEDICAL DIAGNOSTIC EQUIPMENT COVERED.—The standards issued under subsection (a) for medical diagnostic equipment shall apply to equipment that includes examination tables, examination chairs (including chairs used for eye examinations or procedures, and dental examinations or procedures), weight scales, mammography equipment, x-ray machines, and other radiological equipment commonly used for diagnostic purposes by health professionals.

In terms of office staff, I have never received the forms that you have to fill out the first time you are a patient somewhere. I never received a privacy statement. I never received my rights and responsibilities in a format I can read. Ever!

-Christie Gilson, Bethlehem, PA

A recent national study from the Equal Rights Center found that less than one quarter of doctors and hospitals offered large print patient information and only 24 % offered any accessible format. Of the pharmacies tested --99% of pharmacies did not offer information in Braille and if the customer requested an audible prescription bottle, 86 of the 100 pharmacies (4 major prescription retailers in 24 states and the District of Columbia) would not make the accommodation—even if the customer provided it.¹⁴

Pennsylvania women with disabilities are not generally provided these accommodations. In addition, medical information should be easy to understand and communicated in a variety of formats. To assure appropriate healthcare, *correct health information -- in a format the consumer can access -- is critical for all women.*

III. Financial Barriers

Women with disabilities face even more financial barriers than their male counterparts. *While all people with disabilities have significantly lower employment rates than the general population, men are two times more likely than women to be working and therefore have medical insurance coverage through an employer.*¹⁵

Women with disabilities and people who are unemployed or under-employed are also more likely to lack access to transportation which creates barriers when trying to arrive on time to doctors' appointments. In addition, medical providers who work with women with disabilities are difficult to find, especially in rural areas, which accounts for most of Pennsylvania. This coupled with counties who are unable to continue due to lack of funds, puts women with disabilities in an extremely vulnerable position.

Even if women have Medical Assistance, it doesn't mean they can access healthcare.

¹⁴The Equal Rights Center (2011), *Ill-Prepared: Health Care's Barriers for People with Disabilities*, The ERC tested four different types of medical facilities, doctors' offices for the practice of: (a) internal medicine, (b) ophthalmology, (c) dermatology, and (d) hospitals. All of the doctors' offices surveyed were privately run with a staff of no less than three physicians. The ERC conducted 100 tests, testing each of the four types of medical providers in 24 states and the District of Columbia.¹⁴

¹⁵ Office of Disability Employment Policy (ODEP) website <http://www.dol.gov/odep/topics/women.htm> accessed June 14, 2012

IV. Lack of Medical Providers

Some barriers to health care access affect all people with disabilities.

A major issue is simply finding a physician who will agree to treat the person. In theory, a doctor cannot refuse to treat a person who has a disability because the examination will take more time (or cost more money). **However, doctors can refuse to treat the person if they do not feel properly trained.**

“One of the things that just is sort of a knife going through my heart, one of the comments that came back,[is] if it is not tested -- in other words on a licensure exam -- if it is not tested, we don't teach it. Disability is not tested; therefore, it is not taught.”

Suzanne C. Smeltzer, RN, EdD, FAAN
Professor and Director
Center for Nursing Research Villanova University College

As suggested by the comment above, medical professionals may not be properly trained to work with women and girls with disabilities. University-based medical schools and training programs may provide limited training through didactic lectures or clinical training. In addition to inadequate time dedicated to learning how to serve this population, many providers have attitudinal barriers or fears that prevent them from giving (or being willing to give) appropriate care.

Medical providers may not feel they are well compensated enough to provide care. Many people with disabilities rely on Medicaid and or Medicare as their primary insurance. Reimbursement rates are not generally as high as private pay or private healthcare plans. Working with a person with a disability can often require extra time and sometimes extra staff and accessible equipment. Physicians are not adequately reimbursed. In addition, doctors may be fearful of liability issues when treating a person with a disability.

A Core Issue--Respect for Women with Disabilities and their Rights

General comments from women with disabilities reflect this as a very central issue of dignity and respect. Women report they are dismissed. Often a woman with disabilities is not treated like a woman, but as a medical marvel or a child or a condition that needs to be fixed.

Women with disabilities also report they are not spoken to by their doctors: the physicians instead address their caregivers, drivers or family members.

Even if the woman with disabilities doesn't appear to be listening, it is incumbent upon the professional to ensure they are being given the opportunity to participate in their own healthcare.

The result is that **women with disabilities often feel their ADA and HIPAA rights are routinely violated. In addition, due to lack of trained medical professionals,** they report that they come in for a health concern, yet the provider immediately looks to the woman's disability as the cause, failing to do standard diagnostic work, and sometimes missing basic clues to serious illness.

Increased clinical experience working with people with disabilities -- not just theoretical or didactic lectures -- is the most effective tool to ensure that medical staff will provide appropriate and respectful care. Interactive training where "customer service" skills are taught would benefit all patients, particularly those with disabilities.

Conclusion

Women with disabilities and their families, medical professionals, hospitals and health centers, government agencies, educators, insurance companies, foundations and disability advocates across the state have joined forces to work on this significant problem.

ACHIEVA's Disability Healthcare Initiative continues to work on solutions that are possible through our own efforts of education and communication. Unfortunately, that's not enough.

Pennsylvania legislators and policymakers need to help women with disabilities by ensuring access to health care. By educating health professionals and educators about accessibility solutions and through systemic policy change, women are more likely to receive preventative health care, reducing hospital and ER visits and significant costs.

Pennsylvania women and girls with disabilities need:

- medical offices and diagnostic equipment that are physically accessible.
- medical providers who are compensated the added expense of providing accessible communications.
- medical providers who are compensated for the extra time and/or staff.
- trained medical professionals serving people with disabilities.
- more medical home opportunities.
- providers with the appropriate education (didactic and clinical) to treat them.
- consistent transportation to go to medical appointments.

Policy Recommendations

1. Enact legislation to educate, monitor and enforce accessibility requirements through the Americans with Disabilities Act (ADA) for all medical providers.
2. Integrate ADA requirements into licensing requirements for health care professionals and facilities.
3. Enact legislation that requires private health insurers to reimburse providers for the cost of interpreters, captioners, Braille and other ADA required modifications.
4. Ensure that Pennsylvania's women with disabilities can receive a mammogram and other preventative diagnostic tests and imaging.
5. Ensure that Pennsylvania's Medicaid (Medical Assistance) providers are compensated for the additional time and/or staff they may need to adequately meet the needs of their patients with disabilities.
6. Institute a more flexible (part time) medical and dental loan repayment program, **using existing funds**, to incentivize health care professionals to serve people with disabilities and other Medicaid recipients, especially in Pennsylvania's underserved areas.
7. Expand the number of Medical Homes in Pennsylvania for adults with disabilities.

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