

“It’s a simple fact.

**People with
physical disabilities
can’t get
basic health care,**

so they get sick

and die

when they shouldn’t.”



I'm 53 years old and I have an 18-year-old son. I have a degree in broadcast communications and won a Silver Medal for the United States in the 1984 Paralympics discus throw competition.

I have always been a strong, independent person but because I have a disability, for many years I have been unable to get basic health services that many people are able to take for granted.

I've had cerebral palsy since birth and my main symptom is severe spasticity. I've been to gynecological offices that didn't have an adjustable exam table. I had to struggle to get out of my wheelchair and climb onto the table—which is not safe at all.

I've had gynecological exams where they did not take a sample of my cervical cells because they lacked the equipment and expertise to work with me, so I just had to worry whether I had cancer or a pre-cancerous condition.

Because I am unable to stand on my own, for years I was unable to have a valid mammogram, which scared me, and wasted money. For a long time, I just stopped trying.

*ICS Member Manyon Lyons' testimony
to New York City Council, 2015*

About the Blueprint

This Blueprint was created by Independence Care System (ICS), a community-based, nonprofit agency serving the Bronx, Brooklyn, Manhattan and Queens. ICS is dedicated to supporting senior adults and adults with physical disabilities and chronic conditions to live at home and participate fully in community life. We achieve this goal by offering our members the choice of two distinct care management plans: ICS Community Care MLTC, a traditional Medicaid managed long-term care plan, and ICS Community Care Plus FIDA-MMP, a plan for those eligible for both Medicare and Medicaid. The goal of both plans is the same: to keep ICS members healthy, safe and as independent as possible.

This Blueprint is based on a review of the literature; a review of standards for primary care, patient-centered care, ambulatory care, and care directed to other distinct populations (e.g., people with AIDS, LGBTQ people, veterans with spinal cord injuries, people with multiple sclerosis); and interviews and focus groups with people with disabilities, physicians, administrators, and policy experts in the field.

The research and writing process was overseen by ICS senior staff, led by Marilyn E. Saviola, Senior Vice President for Advocacy and the Women's Health Program, with former director of the Women's Health Program Nicole Mylan, along with the members of our Blueprint Advisory Committee. (See Appendix A.) The committee consists of highly-regarded primary care providers, other clinicians, health care administrators, public policy experts, and disability rights activists. The Blueprint was written by Angela Bonavoglia, with research conducted by Caroline O'Neill.

Support for this work was provided by the New York State Health Foundation (NYSHHealth). The mission of NYSHHealth is to expand health insurance coverage, increase access to high-quality health care services, and improve public and community health. The views presented here are those of the authors and not necessarily those of the New York State Health Foundation or its directors, officers, and staff.

A Blueprint for Improving Access to Primary Care for Adults with Physical Disabilities



ICS Member Daniel
Frenkel and his mother,
Ludmila Frenkel

Table of Contents

A Personal Note to Health Care Providers – Rick Surpin	1
Introduction	3
Where to Begin	7
The Physical Plant: What makes a facility accessible? What equipment do I need?	11
Administration: Policies and Procedures	15
Disability Sensitivity and Awareness Training	21
Clinical Expertise	25
A Disability-Competent Model of Primary Care	29
Advocating for Change	33
Conclusion	34
Appendix A: Blueprint Advisory Committee Members and Participating ICS Staff	35
Appendix B: Sample Accessibility Survey Form	36
Appendix C: Resources for Facilities and Equipment Accessibility	43
Appendix D: Resources for Disability Sensitivity and Awareness Training	44
Appendix E: Resources for Clinical Expertise	45
Appendix F: Resources for Patient Education	47



A Personal Note to Providers

Rick Surpin – President, Independence Care System

Though decades have passed since the adoption of federal, state and local anti-discrimination laws aimed at removing barriers to health care for adults with physical disabilities, dramatic disparities in care persist. Even in the face of movements for health care reform, we have seen little progress in making health care accessible for adults with physical disabilities. When policymakers and health care activists talk about ameliorating health disparities for vulnerable populations, adults with physical disabilities and mobility impairments have simply not been on their radar.

With mounting concern about preventing costly emergency room visits and unnecessary hospitalizations, this picture, thankfully, is beginning to change. Today, the issues of health disparities, cultural competency, and how to provide quality care for vulnerable populations are receiving more public attention than ever before. This trend provides a great opportunity to ensure that adults with physical disabilities are included among those vulnerable populations and that their health care needs are at last addressed. In truth, if this fails to happen, we will never achieve the goals of health care reform—to improve the health of vulnerable populations and to manage runaway health care costs.

A nonprofit organization founded in 1999 with the mission of supporting adults with physical disabilities to live independently in the community, Independence Care System has been at the forefront of this work for over a decade. We serve people—our members—who are beneficiaries of Medicaid and Medicare, or Medicaid only, who live in the community and have significant functional limitations. We saw early on that whether they were young, middle-aged or older adults, if our members had the right supports—from health care to home care to the right wheelchair—they could live full, active and independent lives.


But in the course of our work, as we set about providing those supports, we also identified severe gaps in the service system. Working to fill those gaps, we developed our own mobile and community-based wheelchair repair service; instituted specialized care management services for adults with multiple sclerosis, spinal cord injury and dementia; and created what would become a model health access program for women with physical disabilities.

It was our Women's Health Program that became the testing ground for the guidance we present in this Blueprint. A step-by-step guide for primary care providers to expanding access to primary care for adults with physical disabilities and functional limitations, this Blueprint came out of a productive collaboration between ICS and a cadre of devoted physicians, policymakers, administrators, activists, and consumers, including people with physical disabilities, who served as our advisors.

Like many activities at ICS, the Women's Health Program developed from the personal experiences of some of our key staff and members. The program would not have happened if ICS had not taken the time and made the space for our members to be involved in the discussions of what needed to be done, to have their experiences of the shortcomings of the existing health care system and their recommendations for change taken into account. Equally important, it would not have happened without the initiative and personal power of Marilyn E. Saviola, our Senior Vice President for Advocacy and the Women's Health Program, a nationally recognized leader of the disability rights movement, along with her dedicated staff. A post-polio survivor, Marilyn has experienced the cultural invisibility that others with physical disabilities experience; she is well aware that often others see "a wheelchair and a ventilator, but they don't see me."

We have drafted this Blueprint in the spirit of capturing our learnings and making them widely available. While there are many lessons here, one emerged as the most important lesson that we learned. It is that increasing access to care for adults with physical disabilities can be done one step at a time, over time. When this is how access is increased, every step along the way spells improvement—in individual lives, in provider satisfaction, and in the health care system itself.

We hope that you will join us in taking these urgently needed steps.



“A hospital mammography supervisor told me one day, ‘People like you cannot come here.’ When I asked her where I should go, she said: ‘Where people like you go.’”

Marilyn E. Saviola, Senior
VP for Advocacy and the
Women’s Health Program
Independence Care System

Introduction

According to the Centers for Disease Control and Prevention, in 2013 approximately one in five adults in the United States, or some 53 million people, were living with a disability. The most common functional disability was a mobility limitation, reported by one in eight adults.¹ Despite this prevalence, many experts in health care delivery, when talking about increasing access to care, think only of access for people who are uninsured or underinsured, or who face language, literacy, racial, ethnic, geographic or socioeconomic barriers; they do not think of adults with physical disabilities living in the community. Yet while people with disabilities experience many of those same barriers, they also face a broad scope of *additional* impediments to healthcare: widespread facility, equipment and attitudinal barriers.

The Barriers to Care

Barriers to care for adults with physical disabilities are numerous and ubiquitous. They include flimsy, too steep or nonexistent building ramps; doorways that are too narrow; bathrooms, dressing rooms and exam rooms that are too small. Adapted equipment is often absent, hidden away in a closet, or a mystery to staff never trained to use it.

Most providers don't have an accessible weight scale, transfer lift, or exam table that lowers to accommodate a patient in a wheelchair. Standard clinical practices, from breast cancer screening to gynecology exams to imaging tests, have not been adapted to the special needs of people with different physical disabilities. Perhaps most important, preconceived notions, damaging stereotypes, unfamiliarity with people with disabilities, a fear of one day becoming disabled, and a range of common misconceptions about caring for an adult with a physical disability hamper the good intentions of even the most dedicated health care providers to connect with and serve adults with disabilities.

The disparities in access to health care persist, in part, because early on the Disability Rights Movement chose not to focus on the medical sector. Advocates did not want to fuel the commonly held stereotype that people with disabilities are "sick" and incapacitated. The disparities persist because while many pediatricians have become skilled and comfortable treating children with physical disabilities, few primary care physicians have had the opportunity to develop skill and comfort in treating adults with physical disabilities. And the disparities persist because there is little enforcement of the laws that require equal access to health care for people with disabilities.

In fact, no agency is charged with proactively and routinely monitoring health care providers to ensure that they comply with the demands of disability rights laws. Providers are asked to self-report, but they receive little or no guidance as to what it means to be fully accessible. For example, a patient who arrives at a facility that bills itself as accessible might be able to get into the front door, but unable to transfer from wheelchair to commode in the bathroom because of insufficient space, or to get onto a fixed-height exam table. At the same time, adhering to existing laws can be perceived as just too daunting by many providers, in terms of both changes in practice and financial costs.

¹ Centers for Disease Control and Prevention. CDC Newsroom Release. Report provides state-by-state data on disability types. Last updated July 30, 2015. <http://www.cdc.gov/media/releases/2015/p0730-us-disability.html>

Public authorities and monitoring agencies depend on the complaint process to take action for failures to provide accessible health care services. However, as ICS's Marilyn Saviola says, "People with physical disabilities who are sick and need care are *afraid* to complain. They're afraid they'll lose what little health care they have."

Finally, and most importantly, disparities in access persist because adults with the most significant physical disabilities and functional limitations remain invisible to the health care system. Using a wheelchair or a walker, perhaps with spasticity or an unsteady gait, they cannot get into the front door of many facilities, much less find an accessible bathroom, transfer to an exam table, undress unaided, remain still for an MRI, or stand up long enough for a mammogram.

The Consequences

While many adults with physical disabilities have a strong relationship with a specialist who focuses on their particular disability, few have a primary care physician, the type of provider who should be their gateway to the health care system and the coordinator of their care. This lack of access to primary, preventive health services means that adults with physical disabilities too often receive only episodic care in emergency rooms, and suffer from diseases that go undetected and untreated. The results range from delayed diagnosis to advanced illness to premature death.

This lack of access to care for people with physical disabilities has enormous consequences.

- People with physical disabilities have higher rates of obesity, arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol, and stroke.²
- Compared to people without disabilities, those with physical disabilities receive fewer preventive services, including cancer screenings (e.g., Pap tests, mammograms) and preventive dental care.²
- While women with physical disabilities have the same incidence rate for breast cancer as women without disabilities, because of later diagnosis and/or less aggressive treatment, they are one-third more likely to die from the disease.³
- Compared with their peers without disabilities, women with disabilities are less likely to receive routine physical examinations, teeth cleanings, hepatitis B vaccinations, cervical and breast cancer screenings, family planning services and other preventive services to improve their health.⁴
- People with mobility impairments are at great risk of secondary conditions, like pressure ulcers, which go undiagnosed and can result in repeated hospitalizations and even premature death.⁵
- People with physical disabilities are in great need of behavioral health interventions, suffering from higher rates of depression, anxiety, stress, and tobacco use, and are more likely to be victims of domestic violence and other crimes.⁶

² Reichard A, Stolze H, Fox MH. *Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States*. Disability and Health Journal. 2011; 4:59-67. <http://www.ncbi.nlm.nih.gov/pubmed/21419369>

³ McCarthy EP, Ngo LH, Roetzheim RG, Chirikos TN, Li D, Drews RE, Iezzoni LI. *Disparities in breast cancer treatment and survival for women with disabilities*. Annals of Internal Medicine 2006; Nov 7; 145(9):637-645. <http://www.ncbi.nlm.nih.gov/pubmed/17088576>

⁴ Centers for Disease Control and Prevention. *Identifying Tools to Improve Clinical Preventive Services for Women with Disabilities*. <http://www.cdc.gov/ncbddd/disabilityandhealth/features/keyfinding-tools-clinical-preventive-services-women.html>

⁵ World Health Organization, Disability and Health, Fact Sheet No. 352, reviewed December 2015. <http://www.who.int/mediacentre/factsheets/fs352/en/>

In addition, the health of people with physical disabilities is in even greater jeopardy due to the frequently difficult social circumstances of their lives, which make regular medical care, including preventive screenings, even more crucial. Many people with disabilities have low levels of education and employment, high levels of poverty, and many more have problems finding safe, affordable, accessible housing.⁶

Finally, recent research suggests that all-cause mortality rates are higher among adults with disabilities than among adults without disabilities, and that significant associations exist between several types of disability and cause-specific mortality. Researchers have concluded that interventions are needed that effectively address the poorer health status of people with disabilities and reduce their risk of death.⁷

The need for change could not be more pressing.

DEFINITION OF TERMS USED IN THIS BLUEPRINT

PHYSICAL DISABILITY:

A functional limitation—specifically, in mobility—that affects one or more activities of daily living, e.g., bathing, toileting, cooking, walking, transferring, or dressing. (Adapted from the definition of the Americans with Disabilities Act—see <http://www.ada.gov/cguide.htm#anchor62335>.) Sensory (sight, hearing), psychological, cognitive and developmental disabilities also affect function, but this Blueprint focuses on people who have mobility limitations.

PRIMARY CARE PROVIDER (PCP):

As frequently referenced in the literature, a PCP can be a licensed MD with a primary specialty in internal medicine, family medicine, gynecology, or geriatric medicine; a pediatrician working with those over the age of 18 (especially Med-Peds, who have a combined internal medicine and pediatrics specialty); a licensed doctor of osteopathic medicine (DO); a licensed adult or family nurse practitioner; or a licensed physician assistant. (For more, go to <https://www.nlm.nih.gov/medlineplus/ency/article/001939.htm>.)

PRIMARY CARE FOR ADULTS WITH PHYSICAL DISABILITIES:

A level of a health services system that provides:

- entry into the system for all new needs and problems;
- person-focused (not disease-oriented) care over time;
- care for all but very uncommon or unusual conditions;
- the coordination and integration of care, regardless of where care is delivered or who delivers it; and
- a means by which the two main goals of an individual's health status—optimization and equity—can be achieved.

(Adapted from Johns Hopkins Primary Care Policy Center definition. For more, go to <http://www.jhsph.edu/research/centers-and-institutes/johns-hopkins-primary-care-policy-center/definitions.html>)

⁶ Iezzoni LI. *Public health goals for persons with disabilities: Looking ahead to 2020*. Disability and Health Journal. 2009;2(3):111-115. [http://www.disabilityandhealthjnl.com/article/S1936-6574\(09\)00029-6/abstract](http://www.disabilityandhealthjnl.com/article/S1936-6574(09)00029-6/abstract)

⁷ Forman-Hoffman VL, Ault KL, Anderson WL, Weiner JM, Stevens A, Campbell VA, Armour BS. *Disability status, mortality, and leading causes of death in the United States community population*. Med Care. 2015 Apr; 53(4):346-54. <http://www.ncbi.nlm.nih.gov/pubmed/25719432>

I was born in the Bronx and have lived there all my life. My parents were both blind and from the age of 14 until I had to stop working at 33, I worked at Vision Services for the Blind.

Cancer runs in my family. My daughter was diagnosed with breast cancer when she was just 14 years old. She has now been cancer free for four years and recently received a full scholarship to attend NYU. I am very proud of her.

Because of my family history, I have always believed it is best to know as soon as possible if you have cancer so that you can get help, but after 2007 I stopped going for gynecological exams because the experience was so hard. My legs are weak because of the MS and I am unable to place or keep my feet in stirrups for the exam.

This spring I was finally able to get a gynecological exam through HHC's partnership with the ICS Health Access Program. It was wonderful. The table lowered. It had stirrups designed to hold my entire leg securely so I was stable and felt safe. The doctor was patient and kind and he was able to do a proper and thorough exam, which was such a relief to me.

I was also able to get my first mammogram in 12 years. It was great. They lowered the equipment and the nurse helped me position myself and held my back to stabilize me. They found some shadows so I was referred for a breast sonogram, just to confirm that I don't have cancer. I keep asking myself, what if I never went? What might happen to me?

ICS Member Cathy McFadden's testimony to New York City Council, 2015

Where to Begin

Clearly, the failures of the health care system to ensure access must be addressed on many levels, with actions by policymakers, institutional administrators, and program directors, as well as by the health care providers themselves. Regarding the providers, while they care deeply, many have never thought about any of this before, or rarely have had opportunities to interact with an adult with a physical disability. They have had no professional training about what is important, what will improve the experience, or what will safeguard the health and safety of both the patient and the provider. Despite the demands of the law and the great need, there has been little in the way of guidance for providers on how to become “disability-competent.” This Blueprint is designed to fill that gap.

Disability-Competent Primary Care

Disability-competent primary care originated in a rich collaboration between the health care and disability advocacy communities. Consistent with the goals of patient-centered primary care, disability-competent care at its heart:

- treats each individual as a whole person and an individual, not a diagnosis or condition;
- identifies the barriers people with physical disabilities face in the community and in the health care system;
- centers on maintaining the person’s health and wellness while supporting his or her maximum function, independence and ability to live in the community as he or she chooses;
- responds to the person’s physical and clinical needs while also considering his or her emotional, social, intellectual, and spiritual needs; and
- encourages an interdisciplinary approach, with health care professionals collaborating across disciplines and care settings, over time.

This Blueprint was written to introduce primary care practitioners in any environment—a group practice, community health center, or major medical center—to the five critical elements of providing disability-competent primary care. And while adults experience many types of disabilities—from vision and hearing loss to mental health, developmental and intellectual disabilities—this Blueprint focuses on a segment of this population that is particularly underserved by primary care providers: persons with physical disabilities, that is, functional—specifically mobility—impairments. (See Definition of Terms.)

The Five Critical Elements

The five critical elements addressed in this Blueprint are:

- The Physical Plant: What makes a facility accessible? What equipment do I need?
- Administration: Policies, Procedures, Staffing
- Disability Sensitivity and Awareness Training
- Clinical Expertise
- A Disability-Competent Model of Care

For each area discussed, you will find:

- foundational, short-term, more easily achievable steps you can take to begin providing disability-competent primary care to adults with physical disabilities; and
- advanced, more challenging, longer-range steps you can take to further build your disability competence.

There is no need to approach these steps in the order in which they are presented. You can begin where it makes sense for you to begin and have good results. For example, in the best of all possible worlds, facilities and equipment would be fully compliant before practice changes. But this may not always be possible. In fact, based on the experience of ICS, practice can change first, with positive outcomes.

In 2008, staff of ICS's Women's Health Program partnered with several leading New York City health care facilities to increase access to breast cancer screening for women with physical disabilities. Once committed to the program, the institutions agreed to have ICS conduct disability awareness and sensitivity training for their staff; to modify their intake and other policies and procedures to address the needs of women with physical disabilities; to set aside designated blocks of time to see these new patients; to work with the available physical space, rearranging furniture and clearing pathways; and to implement creative solutions to improve accessibility, such as facilitating a mammogram by using Velcro straps to hold a woman's arm in place when she is unable to hold it in place herself. So before any facility upgrades were made or new equipment purchased, many women with physical disabilities were deeply heartened to be seen for mammograms, breast ultrasounds, biopsies and clinical exams in sensitive, welcoming environments by disability-competent physicians and support staff.

At the same time, any practice that moves through all of these steps, foundational and advanced, will be meeting what we expect, in time, will be the basic standards for a certified Center of Excellence in Primary Care for Adults with Physical Disabilities, once an official governing body formally establishes those standards. Such centers will be vital places where the model of disability-competent care can be further developed, where research leading to evidence-based practice can be conducted, and where other health care providers can be trained to learn and to provide quality care to adults with physical disabilities.

It is true that becoming a Center of Excellence will not be the goal for many who open this Blueprint. It is also true that any provider who takes even some of these steps will be helping to reduce the troubling health care disparities still experienced by adults with physical disabilities and to move our nation closer to modeling a truly equitable and inclusive health care system.

ICS RESOURCES FOR HEALTH CARE PROVIDERS AND CONSUMERS WITH DISABILITIES

For health care providers

In addition to this Blueprint, ICS offers a number of resources, listed below, to help providers increase access to care for adults with physical disabilities. All are available free of charge on the ICS website, except for the Training Manual, which may be purchased from ICS. If you are interested in purchasing the manual, please call (718) 907-1614 or email whp@icsny.org. The address of the ICS website, where you can download the free materials, is <http://www.icsny.org>. ICS also offers consultation, training, technical assistance, and help with accessibility assessments. For more information, call (718) 907-1614 or email whp@icsny.org.

■ **Disability Sensitivity and Awareness Training for Women’s Health Care Providers, ICS Training Manual for Facilitators** — A two-hour lesson plan on disability sensitivity and awareness, adaptable to all health care providers, not only those working in women’s health. Features six training activities (with handouts) and scripts for role plays (e.g., patient and reception staff, patient and provider in exam room, etc.). To purchase, call (718) 907-1614 or email whp@icsny.org.

■ **ICS Sample Accessibility Survey Form** — A seven-page worksheet to aid in assessing facility and equipment accessibility (also available in this Blueprint, Appendix B).

■ **Breaking down Barriers, Breaking the Silence: Making Health Care Accessible for Women with Disabilities** — ICS and New York Lawyers for the Public Interest, October, 2012. Analysis of existing barriers and accessibility laws, with policy and practice recommendations for change. See <http://www.icsny.org/sitemanagement/wp-content/uploads/2012/10/BreakingBarriers.pdf>

■ **Breast Cancer Screening Project for Women with Physical Disabilities: A Report on Preliminary Findings** — April 1, 2008 to March 31, 2010. Based on the early experiences of ICS’s Women’s Health Program, with lessons learned and recommendations for replication. See http://www.icsny.org/sitemanagement/wp-content/uploads/2009/09/FINAL-KOMEN_report.pdf

For consumers

ICS offers a number of tip sheets for consumers, listed below, available free of charge on the ICS website. Unless otherwise noted, all tip sheets are available in English, Spanish and Russian. The ICS web address is <http://www.icsny.org>.

■ **Wheelchair Maintenance** – http://www.icsny.org/sitemanagement/wp-content/uploads/2009/09/Tip-Sheet-Keep-Moving-FINAL_English.pdf


■ **Women with Disabilities and Breast Cancer: Know Your Rights (available in English and Spanish only)** – http://www.icsny.org/sitemanagement/wp-content/uploads/2013/11/Breast-Cancer-Flyer_FINAL.pdf

■ **Fall Prevention** – http://www.icsny.org/sitemanagement/wp-content/uploads/2009/09/Tip-Sheet-Fall-Prevention_English.pdf

■ **Prevent Pressure Ulcers** – <http://www.icsny.org/sitemanagement/wp-content/uploads/2014/05/MMP-Tip-Sheet-Pressure-Ulcer-FINAL-04.07.14.pdf>

■ **Caring for a Loved One with Dementia** – http://www.icsny.org/sitemanagement/wp-content/uploads/2009/09/Tip-Sheet-Dementia_English.pdf

■ **Have a Great Relationship with Your Home Care Worker** – http://www.icsny.org/sitemanagement/wp-content/uploads/2009/09/Tip-Sheet-Home-care-FINAL_English.pdf



“My visits to doctors in the past were always preceded by anxiety. I had concerns about whether I’d have access to the facilities—not just the front door, but to elevators, bathrooms, exam rooms, dressing rooms—about the height of the exam table, about the attitudes of staff. . . Getting health care was very difficult.”

Kim Yancey
Grievance Specialist
Independence Care System

The Physical Plant

What makes a facility accessible? What equipment do I need?

Current laws require that all medical providers ensure “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...unless such a requirement would fundamentally change the nature of the program or would result in an undue financial and administrative burden for the facility.”⁸

The major laws requiring accessibility include: the Americans with Disabilities Act of 1990, which prohibits discrimination against people with disabilities in everyday activities, including medical services; Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination in programs and activities, including health programs and services that receive federal aid (e.g., Medicare and Medicaid); and most recently, the Affordable Care Act of 2010 (civil rights provision, Section 1557), which prohibits discrimination based on disability and covers any health program or activity that receives funding from the US Department of Health and Human Services (e.g., hospitals or doctors accepting Medicare), the health insurance marketplaces, issuers that participate in the marketplaces, and any health program that HHS itself administers. Various local and state civil rights laws also apply.

While there is a cost to accommodating the required changes, these costs are not nearly as high as some fear. The anticipated costs tend to fall into two categories. First, some, though not all, adults with physical disabilities will require a longer appointment. While that extra time is not sufficiently reimbursed by insurers, disability rights advocates are working hard to change this picture and you can help. (See *Advocating for Change*.) Second, there are the costs associated with facility upgrades and equipment. In fact, providers can get help with those costs by taking advantage of federal tax credits and deductions granted specifically for making services and facilities accessible.

- The Disabled Access Credit provides a non-refundable credit for small businesses that incur expenditures for the purpose of providing access to persons with disabilities. (See Form 8826, Disabled Access Credit <https://www.irs.gov/pub/irs-pdf/f8826.pdf> for information about eligible expenditures.)
- The Architectural Barrier Removal Tax Deduction was created to encourage businesses of any size to remove architectural and transportation barriers to the mobility of persons with disabilities and the elderly. (See Publication 535—Item #7, Barrier Removal, www.irs.gov/publications/p535/index.html.)

Businesses may use both the Disabled Tax Credit and the Architectural Barrier Removal Tax Deduction in the same tax year if the expenses meet the requirements of both sections. See Appendix C for additional related resources.

In addition, practitioners and institutions that make their services accessible will be moving into the future, into the world of “universal design.” Rather than focusing on what must be done to accommodate the needs of people with physical disabilities per se, universal design ensures that health care facilities and equipment will be accessible to all people, of any age, regardless of the genesis or duration of their particular temporary or permanent functional impairment. At the same time, it bears noting that as the population ages, the number of people who will experience physical disabilities and need accommodations and support services is rapidly growing.

⁸ *Breaking down Barriers: Breaking the Silence: Making Healthcare Accessible for Women with Disabilities*, ICS and New York Lawyers for the Public Interest, October, 2012

The Goal

Ensure that facilities and equipment are accessible to adults with physical disabilities and that all environmental barriers to the delivery of timely, ongoing and appropriate primary care are removed.

FOUNDATIONAL STEPS

- Conduct an environmental assessment of your facility and equipment, putting in place a plan and timeline to increase accessibility. (See Appendix B for a sample accessibility survey form.)
- Ensure that there is an accessible entrance to your office.
- Ensure that there is at least one accessible bathroom.
- Have available at least one exam room that is large enough for an adult in a wheelchair to transfer from the chair to the exam table, and to accommodate a family member or aide.
- Provide a patient transfer lift (e.g., freestanding or track-type) and ensure that staff are trained to use it.
- Provide an adjustable-height exam table with add-on equipment to aid in positioning (e.g., side rails, safety belts, adjustable padded stirrups, head and foot rests).
- Provide a wheelchair-accessible platform/roll-on weight scale, which will also accommodate a person who has difficulty standing and needs to hold on.
- Make available positioning and support aids, such as wedges, rolled up blankets, Velcro straps.

ADVANCED STEPS

Below are sample advanced steps you may want to consider. For resources on additional strategies for making facilities and equipment accessible (including a link to *Removing Barriers to Health Care: A Guide for Health Professionals* by the Center for Universal Design and the North Carolina Office on Disability and Health, from which some items below are drawn), see Appendix C.

Building access

- If accessible entrance is separate from the main entrance, directional signage is clearly visible.
- Facility, at the entrance and in the interior, has power door openers.
- There is a curb cut to the sidewalk that leads to the building entrance.
- If there are steps to the entrance, there are handrails for unsteady people.
- There is at least one wheelchair accessible path from the entrance to the exam room.
- There are nonslip ramps, with slopes accessible for wheelchair access, and sturdy, accessible railings.
- Elevators are accessible, with doors that remain open a minimum of 5 seconds.
- Buttons and controls to doors are located in hallways, and those in elevators are no higher than 42 inches.

Bathrooms


- Accessible stall is at least 60 inches wide so a person using a scooter or a wheelchair can transfer inside the stall.
- Toilet is higher than a standard height.
- Toilet has auto flush.
- Faucets can be turned on and off with one hand or a closed fist.
- Soap dispenser can be activated by a person who uses a closed fist.

Reception and other areas

- Reception desks/front counters are at eye level with a person in a wheelchair so that the person can communicate directly with the receptionist.
- There are open floor spaces where people using wheelchairs, scooters, or strollers can easily wait, without being in the way of ongoing traffic and without being isolated from other patients.
- There is an area where a power wheelchair can be plugged in to charge.
- At least 27 inches of “knee space” is available below work surfaces, such as reception desks, so that the legs of people using wheelchairs can fit comfortably underneath.
- Consultation areas/offices are big enough to accommodate wheelchair users.
- If no dressing room is accessible, there is a nearby, private room where the person with a disability can change or they are able to do so in the exam room.

Equipment and Supplies

- Catheters are available in the exam room (e.g., for GYN patients who might benefit from pre-exam catheterization).
- Emergency equipment is available for wheelchairs (e.g., back-up manual wheelchair, charger for wheelchair batteries).
- A crash cart is available for medical emergencies (e.g., autonomic dysreflexia).
- Different height chairs are in the waiting area, with padded arms for people who need help rising.



“Having a primary care provider means that you’ll have a place where the people are familiar with you, where they won’t see you anymore as a ‘problem.’”

Participant
Patient Focus Group

Administration

Policies and Procedures

The commitment to providing disability competent primary care to adults with physical disabilities also extends to modifying administrative policies and procedures, particularly those related to scheduling appointments and managing intake and reception.

The Goal

To identify the person's functional limitations, document the accommodations required, and ensure that those accommodations are provided as well as modified, as needed, over time.

FOUNDATIONAL STEPS

- Embed questions that assess the functional abilities of the patient with a disability as well as the modifications required for the conduct of an exam in intake forms. (See Making a Functional Assessment—Sample Questions.) At the same time, bear in mind that not all patients with physical disabilities will require special accommodations or present with very complex conditions; this is why the functional assessment is so important.
- Record accommodation information in the patient's chart so that the patient does not have to repeat their needs every time they visit.
- Send the intake form out to the patient so that you receive it in advance of the appointment and can plan accordingly (e.g., for an extended appointment, extra staff, booking a specific exam room or specific equipment).
- Let the patient know who will act as their point of contact in advance of and on the day of their appointment.
- Assist patients as needed in arranging transportation to their appointment and ensure that on the day of the appointment, especially if the patient is leaving the appointment after 5 p.m., that the patient has transportation home. Transportation can be extremely challenging for people with physical disabilities, who often require an ambulette or special services (e.g., paratransit) to travel. Such transportation generally has to be scheduled 24 to 48 hours in advance, affording patients limited flexibility for last-minute changes in appointment times.
- Minimize long waiting times to be seen on appointment day, which can be particularly onerous for adults with physical disabilities. They may have incontinence, be unable to sit upright or still for a long time, have severe muscle spasms, be left without a personal care assistant if the assistant goes off duty during the waiting time, or miss a transportation pick-up and have to wait, sometimes hours, for a rescheduled ride. Conversely, because of unavoidable delays in the arrival of transportation to take patients to their appointment, they may, despite their best efforts, arrive later on some days than their scheduled time.
- Arrange for the patient to receive as many services as possible in the same place, if accessible rooms are scarce. (For example, take vital signs, weight, in the same room as the physical exam is held.)

-
- Schedule multiple appointments for different procedures/exams in different parts of the same facility on the same day, if possible, and if the patient agrees that this will be helpful.
 - If patients are accompanied by a personal aide, be sure that the patient has the opportunity, in private, to make their wishes known as to when and whether they are comfortable having the aide or other accompanying person involved in the intake process or exam.

ADVANCED STEPS

- Develop scripts for intake workers, which can be helpful in ensuring sensitivity and a comfort level in communicating with patients with disabilities.
- Review policies, practices and procedures other than intake, scheduling and appointment day practices to ensure that the needs of patients with physical disabilities are identified and addressed.
- Designate specific blocks of time to be allocated for longer appointments, using those times for your patients with physical disabilities who need additional time and help.
- Document and maintain functional assessment and accommodation information through electronic medical records software, which will facilitate recording, managing and sharing the information.

MAKING A FUNCTIONAL ASSESSMENT—SAMPLE QUESTIONS

The following are among the questions that may help with determining a patient's special needs and how much staffing and time will be required to meet those needs.

General intake

Do you use a mobility aid?

What type of mobility aid—manual/motorized wheelchair, scooter, walker, cane?

If you use a wheelchair, are the armrests/leg rests removable?

Do you need assistance with dressing/undressing?

Do you need assistance getting onto an exam table?

Do you need a transfer lift to get onto a table?

For a specific exam, e.g., a mammogram

Can you stand and for how long?

Can you raise your arm without assistance?

Do you have any spasticity?

Do you take medications for spasms?

Staffing

The most important requirement—whether for a small practice or a Center of Excellence in Primary Care for Adults with Physical Disabilities—is for the staff to work well as an interdisciplinary team.

The Goal

Clinical and support staff working together to deliver comprehensive, coordinated, and integrated care.

FOUNDATIONAL STEP

Disability-competent medical staff to provide direct, clinical primary care. See the chapter on Clinical Expertise for foundational clinical knowledge and foundational clinical skills needed to provide disability-competent primary care to adults with physical disabilities.

ADVANCED STEP

Disability-competent support staff who collaborate with the primary care provider and assist with care coordination, ensuring that patients have the health care services as well as the behavioral, social and support services they need to live independently in the community.

- Some support staff functions are clinical, requiring clinical expertise, and can be performed by people with various educational backgrounds and experience (e.g., social worker, nurse practitioner, RN, physician assistant).
- Other support staff functions are critical coordinating functions, which can be performed by trained non-clinicians with various educational backgrounds and experience (e.g., patient navigator, executive assistant, intake worker). The number of support staff required will depend on such factors as the skill and interests of existing staff, the availability of staff outside of the primary care practice to help, and the number of adult patients with physical disabilities in the care of the practice.

Regarding panel size, common wisdom has it that to achieve expertise in the care of patients from a particular population, it is necessary that 100 patients, or 20 percent of an individual provider's patient panel, represent that population. Achieving this level of practice can be a challenge because building knowledge and skill working with adults with physical disabilities, understanding their conditions and implications, takes time. Clinical experience can only be amassed over time, and it is essential to establishing and sustaining this basic knowledge and skill. It is suggested that practitioners begin simply with one or two patients and then allow the practice to grow at a level that is comfortable for the practitioner and their support staff.

Disability Sensitivity and Awareness Training

Despite the pressing need for medical facility staff across disciplines to be trained to competently work with adults with physical disabilities, studies confirm that little formal curriculum exists in medical schools, nursing schools and training programs for allied health professionals (such as radiologic technologists). In the absence of a systematic approach to training health care professionals in disability sensitivity and awareness, other avenues of training need to be offered to help fill that critical gap.

The Goal

To establish a vehicle for educating staff to become knowledgeable, sensitive, and comfortable providing disability-competent primary care to adults with physical disabilities.

FOUNDATIONAL STEPS

- Mandate site-wide, cross-departmental disability awareness and sensitivity training for all employees who interact with patients—from physicians, nurses, social workers and other allied health professionals to reception, clerical, security, maintenance, transportation, guest relations, finance and other support staff.
- Develop and deliver an introductory disability awareness and sensitivity training session, which can be done in as little as a few hours, conducted by outside expert training facilitators or in-house by existing staff, using existing resources. (See Appendix D for a selection of training resources.)
- Ensure that the training environment is perceived as emotionally “safe” for staff; that the training is participatory, giving staff the opportunity to role play; that there is some way for staff to witness the patient experience (e.g., in a video, a live presentation); and that staff, patients or consultants with physical disabilities help facilitate the training.
- Educate appropriate staff to know where the accessible bathrooms are; where the accessible exam rooms and procedure rooms are and how to book them; and what the accessible equipment is, where it is, and how to set it up, use it safely, and maintain it.
- Incorporate disability sensitivity and awareness training, with the participation of people with physical disabilities, into your ongoing cultural competency and diversity training program, conducting it at least annually so that all new staff are trained.
- Evaluate staff disability competency on an ongoing basis, establishing ways to measure the success of the training (e.g., pre-and post-tests of knowledge and attitudes) and success at meeting established performance goals.
- Get feedback from your patients with physical disabilities about their impressions of care in your practice and integrate that feedback into your training program.



“There are a lot of biases we have if we see someone in a wheelchair, like ‘this person is going to take a lot of my time.’ . . . We assume a complicated medical history, multiple admissions, multiple medications—which may not even be the case. . . . We project our uncertainty and discomfort with care onto the patient. We don’t know how to do a comprehensive assessment of someone with a disability in a timely fashion. What it really points to is the great need for education.”

Primary Care Physician

“It’s not that anyone means to be unhelpful; it is simply a lack of awareness and knowledge that interferes with providing compassionate, quality care... We have got to educate staff, doctors, nurses, assistants, transporters, clerks, everybody. Because if we provide education, then we give staff the opportunity to develop an awareness of the needs of these patients. And our responsibility as providers is to meet those needs.”

Hospital Administrator

INTRODUCTORY DISABILITY SENSITIVITY AND AWARENESS TRAINING: BASIC CONTENT*

- Understanding the person with a physical disability (e.g., where the disability fits into the person's life; their values and expectations about the future).
- A wellness frame for care, replacing the notion of the person with a physical disability as "sick" and having a poor quality of life, with an emphasis on prevention, wellness, and support for maximum function and independence.
- The specific health care needs of people with disabilities, and the social, environmental, attitudinal and communication barriers to health care access.
- The Disability Rights Movement and the Americans with Disabilities Act.
- Demystifying disability (e.g., beyond the health care services needed to manage a disability, the adult with a physical disability has the same primary care needs/issues as everyone else).
- Disability sensitivity and language (e.g., surfacing and replacing negative words, addressing the importance of "person first" language; e.g., "a person with a disability" vs. "a disabled person").
- Misconceptions providers have about caring for adults with physical disabilities and guidelines for basic interactions. (See Eight Common Misconceptions.)
- Patients' rights and providers' responsibilities in terms of what the law requires.
- Community-based long-term services and supports (e.g., home care, mobility equipment) that are crucial to the ability of adults with physical disabilities to live full, active and independent lives.

*Primary source: ICS Training Manual for Facilitators <http://www.icsny.org>

EIGHT COMMON MISCONCEPTIONS ABOUT CARING FOR AN ADULT WITH A PHYSICAL DISABILITY

I tell patients who I know have a disability that they have to bring someone with them to help at the appointment.

REALITY: Patients with disabilities may choose to bring a family member, friend, or a personal aide, but they cannot be told they must do so. Should they bring someone, that person is not required to assist in any way. The provider must ensure that the patient has the assistance he or she needs with filling out forms, dressing and undressing, transferring to the exam table or other equipment, maintaining balance or position while on the table or equipment, etc.

If the person with a disability comes to us with a personal aide, obviously it's best to talk to the aide.

REALITY: Providers should always speak directly to the patient regarding his or her care, and offer the patient who is accompanied by an aide or another companion the opportunity to talk in private. Also, being in a wheelchair doesn't correlate with having a hearing impairment or a cognitive deficit, so do speak in a normal tone of voice, from a seated position whenever possible, so that the two of you can be at eye level.

I can't help anyone onto the exam table; I have a bad back, and it's dangerous for me. Besides, helping to transfer the patient would be a legal liability.

REALITY: You must examine a patient with a disability as you would any other patient, but staff should be protected from injury by having accessible medical equipment and proper training on safe transfer techniques. In addition, if one staff member is unable to assist in transferring, there must be another qualified staff member available. Legal liability comes into play when providers refuse to examine a person because of a disability.

Our tables don't go up and down, so we just examine people in their wheelchairs, which is fine.

REALITY: Sometimes it is, but sometimes it isn't. Examining a patient in his or her wheelchair does not provide equal access to care when the examination is less thorough in the chair than on the exam table. If an examination would not require a person to lie down, such as an examination of the face, and the exam table is not important, the person may remain seated in their chair.

Once the patient is on the exam table, it's pretty standard procedure in terms of how to position them.

REALITY: Actually, adults with physical disabilities know the best ways to move or position their bodies to avoid pain, which may not be immediately apparent to a provider (e.g., a paraplegic person cannot pull a leg away if a position is painful, but can alert the provider in advance to avoid that particular position). Before moving to position the person for a procedure or an exam, first ask him or her what is the best way to do that.

Wheelchairs take up a lot of room in our waiting area. Sometimes I just move the chair, to get the person out of the way.

REALITY: This is never appropriate; it is like moving someone's body or belongings without their permission. In addition, space should be made in the waiting areas for a person in a wheelchair to be comfortably seated. If there is a need for someone to pass near to where they are, just ask them politely if they would mind moving for a moment and apologize for the inconvenience.

The weight of a person with a disability doesn't matter the way it does with other patients.


REALITY: Weight is as important to assessing the health of a person with a disability as it is with any other patient—an accurate diagnosis and/or treatment/medication regimen can depend on it; accessible weight scales are essential pieces of equipment.

No need to talk to her about birth control or having children; she doesn't have sex, I'm sure, so she doesn't need birth control, and she certainly shouldn't be thinking about having children.

REALITY: Women with physical disabilities—as well as men—need to be recognized as sexual beings and their sexual and reproductive health and needs addressed. Information and access to all forms of birth control should be provided, and women with disabilities, as with all women, should be cared for sensitively during pregnancies and childbirth.

ADVANCED STEPS

- Designate clinical staff to provide hands-on training and coaching in specific departments and aspects of care (e.g., transferring the patient using a lift), persons who other staff know are the experts and who are available if questions arise.
- Bring in expert staff—e.g., in rehabilitation—to further educate primary care staff in the needs/challenges faced by adults with mobility impairments, including the correct operation of mobility equipment and how to troubleshoot common problems (e.g., how to disengage brakes so that a wheelchair can be pushed, how to check a wheelchair battery).
- Explore training opportunities with local agencies (e.g., a primary care team can visit a long-term care facility for a few days for training in such tasks as transferring).
- Identify “program or patient champions,” people who feel passionately about caring for adults with physical disabilities, who will model disability competency, who will support staff in their new roles, and who will ensure that patients are being treated in a disability-competent manner.
- Attend continuing education programs focused on various aspects of providing primary care to adults with physical disabilities.
- Develop a continuing education program and have it authorized as a Continuing Medical Education Unit (CME) for physicians or a Continuing Education Unit (CEU) for professionals in related health disciplines, and deliver the training to providers for a fee.
- Offer fellowships, internships, and field practicums in disability-competent care; have experienced physicians mentor less-experienced physicians; and rotate medical students and nurse practitioners through your practice, training as students are trained in academic hospitals.
- Link to local nursing schools and medical schools and work with them to inform them of the need to augment curriculum to include disability competency.

A portrait of Jean Minkel, PT, ATP, a woman with short grey hair and glasses, wearing a black and white striped shirt and a pearl necklace. She is looking directly at the camera with a slight smile. The background is a plain, light-colored wall with a framed picture visible in the distance.

“The parts of the body of a person with a physical disability that function properly are as important as the parts that don’t. You want to keep those working parts working well.”

Jean Minkel, PT, ATP
Senior Vice President
Rehabilitation Services
Independence Care System

Clinical Expertise

To provide disability-competent care to adults with physical disabilities requires that clinicians consider factors beyond standard, evidenced-based treatment protocols. In some cases, applying those protocols will work; in other cases, it will not. For example, well-meaning providers who are unfamiliar with people with physical disabilities may shy away from providing standard treatment approaches for fear they will have a negative impact on the person's health. Such a provider may prescribe a lower dose of a particular medication, concerned that the standard dose will harm the patient. But instead of helping, this strategy can leave the patient vulnerable and ultimately untreated.

Alternately, other providers might use a standard protocol without realizing the harmful impact that protocol can have on the patient because of his or her physical disability. For example, broad-spectrum antibiotics commonly cause diarrhea. Patients who need help, and perhaps a mechanical or power lift, to transfer from their wheelchair to a toilet in an accessible bathroom are often left soiled for prolonged periods of time. This leaves the patient feeling humiliated, socially isolated, and at risk of developing such secondary conditions as a pressure ulcer or a urinary tract infection. If the treatment choice cannot be avoided, a provider can add another medication to decrease the common side effects; e.g., starting an anti-diarrhea medication along with a broad-spectrum antibiotic may reduce or prevent this scenario.

While challenging, the diseases and conditions experienced by people with physical disabilities can be effectively managed; what is essential is that providers take the disability into consideration when determining treatment interventions and medication regimens. With that in mind, below you will find the foundational clinical knowledge and foundational clinical skills needed to provide disability-competent primary care to adults with physical disabilities. Of course, not every practice that embarks on increasing access to primary care for adults with physical disabilities—or that aims to create a Center of Excellence—will have all of the following clinical expertise at the start. What is most important is to create a process for building knowledge and clinical competency over time. Fortunately, there is a growing list of clinical resources in the form of professional organizations that focus on particular disabilities or conditions, as well as more generic organizations that provide consultation and assistance to physicians and other health professionals on expanding access to care for adults with physical disabilities. (See Appendix E.)

The Goal

To provide high quality, disability-competent clinical care to adults with physical disabilities.

FOUNDATIONAL CLINICAL KNOWLEDGE

- Knowledge of diagnoses that limit physical functioning, particularly for those who are the most underserved by primary care providers. While not an exhaustive list, the most common diagnoses experienced by patients with mobility impairments are: cerebral palsy, congenital orthopedic conditions, multiple sclerosis, muscular dystrophy, Parkinson's disease, post-polio syndrome, rheumatoid arthritis, spinal cord injury, spina bifida, and traumatic brain injury.
- Knowledge of common secondary conditions that are risks for particular disabilities, such as:
 - UTIs, falls, depression, chronic fatigue—e.g., risks for those with multiple sclerosis;
 - decubitus ulcers, autonomic dysreflexia,—e.g., risks for those with a SCI;
 - osteoporosis/fractures—e.g., risks for all non-weight-bearing patients;

- aspiration pneumonia and upper respiratory infections—e.g., risks for quadriplegic patients;
- obesity, hypertension, diabetes—e.g., risks for those with mobility limitations;
- rotator cuff tears—e.g., risks for manual wheelchair users; or
- other ambulatory care sensitive conditions,⁹ many of which are not disability-specific but result from functional limitations.
- Knowledge of equipment and medical supplies used by people with physical disabilities (e.g., wheelchairs, ventilators, urinary catheters), including how they address functional impairments and their impact on examinations and interventions.
- Knowledge of specialists and community resources to which patients can be referred—and from which patients can be referred—and a willingness to collaborate closely with those resources, particularly when patients transition from one community setting (e.g., home) to another (e.g., hospital, rehab facility).
- Knowledge of advance care planning (including dealing with special circumstances, e.g., the need to modify living wills for those who already use a respirator or have a feeding tube).

FOUNDATIONAL CLINICAL SKILLS

- Perform a routine full systems review, using age-related normative diagnostic information to establish the patient's health status (e.g., body weight, blood pressure, routine blood panel, urinalysis), just as would be done for any other patient.
- Identify and employ interventions to reduce secondary conditions that commonly occur due to the disability or condition (e.g., arrange for a pressure-relieving wheelchair cushion for patients at risk of skin breakdown; pneumonia vaccine for quadriplegic patients at risk of upper respiratory infections).
- Perform behavioral health screenings (e.g., for depression; domestic violence; alcohol, tobacco, substance misuse; caregiver abuse); make appropriate referrals when screenings indicate a risk or an underlying issue.
- Collaborate with colleagues to arrange for additional screenings as needed, based on the special risks faced by patients with specific diagnoses (e.g., bone density tests to detect early onset osteoporosis for non-ambulatory patients; urodynamic studies to prevent UTIs for persons with neurogenic bladder).
- Adapt equipment and procedures to the conduct of essential screenings and routine exams for patients with different functional limitations (e.g., mammograms, GYN exams, colorectal exams), making modifications as needed (e.g., Pap smear from a sideways position).
- Take a comprehensive medication management approach.
 - Consider the disability when prescribing and ordering treatment, anticipating the impact of side effects in relationship to the person's disability, then taking steps to minimize those side effects or seeking equally effective alternatives with fewer side effects, when possible. (For example, initial treatment for hypertension often includes a diuretic, but for a patient with an ataxic, slow gait, increased frequency and urgency of urination can result in incontinence and falls.)
 - Assess the patient's ability to follow their medication regimen, ensuring that they have the medication management assistance they need. This can range from a medication case to bubble-

⁹ ACSCs have been identified by the Agency for Healthcare Research and Quality as conditions for which good outpatient care can potentially prevent the need for hospitalization, or for which early intervention can prevent complications or more severe disease. For more, go to <http://www.ahrq.gov/downloads/pub/ahrqqi/pqiguide.pdf>

wrapped dosing, from educating a patient/care partner about the treatment requirements to linking the patient to a visiting nurse or home care agency if they have no assistance in place.

- Ensure that supports are available prior to starting treatment. Treatment that begins prematurely, without the resources the patient needs to adhere to the treatment regimen, is doomed to fail. (For example, six weeks of antibiotics, administered every four hours, is required to treat osteomyelitis, an infection of the bone that can occur with pressure ulcers; this can be impossible for the patient who is immobile, has poor fine motor coordination, and no one such as a visiting nurse to help, resulting in an inability to adhere to the regimen, sepsis, and hospitalization.)

WHEN PEDIATRICIANS TRANSFER PATIENTS TO AN ADULT PCP*

For adults with physical disabilities being transferred from a pediatrician to an adult primary care practice, the pediatrician should send the PCP a written care plan that may include:

- Summary of medical information (e.g., history of hospitalizations, procedures, tests)
- Patient's current list of providers, medical equipment and medications, and special care needs
- Obstacles to transitioning to an adult care clinician
- Information provided to the patient about the transition of care, and patient's response to the transition
- Arrangements for release and transfer of medical records to the adult care clinician

*Excerpted from the National Committee for Quality Assurance (NCQA) Patient-Centered Medical Home standards and guidelines

ADVANCED CLINICAL KNOWLEDGE AND SKILLS

- Provide ongoing, hands-on teaching, coaching, mentoring, and shadowing for new staff.
- Establish a Continuous Quality Assessment/Improvement Program to identify the health care needs of this population in accessing preventative services and screenings, including services needed as the patient ages with a disability, to address these health care needs and evaluate clinical outcomes.
- Seek opportunities to participate in research projects designed to show that community-based, long-term care reduces hospitalizations, which will help marshal the evidence that will increase reimbursement for community-based care. Pair with an institution to compare the costs of caring for someone in a hospital versus providing care at home.
- Establish or participate in an existing “learning collaborative” through which you and your staff can share insights, develop new skills, document outcomes, and contribute to a growing body of best practices and evidence-based care with other medical professionals, health centers, or hospitals.
- Consider joining Project ECHO® <http://echo.unm.edu/about-echo> (Extension for Community Health Care Outcomes), an online learning community and new model of post-professional training. Project ECHO provides a framework for primary care providers to teach and learn by sharing cases and best practices when working with patients with specific health care needs.
- Write position papers and articles for major health care publications (e.g., *American Journal of Public Health*, *New England Journal of Medicine*, *Journal of the American Medical Association*, *Journal of Advanced Nursing*, *The Nurse Practitioner*) about the health care disparities that exist for people with disabilities, the ways in which lives and health are jeopardized, what you have found works to improve health and lives, and how to make the best use of health care resources.



Israt Noor
ICS Member

A Disability-Competent Model of Primary Care

“Rather than focusing on a diagnosis—such as spinal cord injury, multiple sclerosis, or mental illness—disability-competent care focuses on providing care and supports for maximum function and addressing the barriers to integrated, accessible care. Meeting the needs of this population requires special attention to an individual’s expectations of independence and autonomy, as well as his or her participation in work, school, and community or social activities.”

Disability-Competent Care Self-Assessment Tool¹⁰

Creating a disability-competent model of primary care for adults with physical disabilities begins with ensuring that patients are empowered to take the lead in decision-making regarding their own health care—what one patient described as “nothing about me without me.” It also requires ensuring that patients have a clear understanding that they approve their plan of care and that they can request changes to their plan at any time. Beyond that, this model of care focuses on what the patient needs to live as independently as possible in the community. These and other qualities of a disability-competent care model are shared by a patient-centered care model, as long as the patient-centered model addresses the special barriers to care and accessibility issues experienced by adults with physical disabilities.

The Goal

To implement a disability-competent model of primary care by taking a biopsychosocial as well as a health care approach to identifying patient needs; providing patient education with an emphasis on steps patients can take to maintain their own health and wellness; and establishing community partnerships and links to accessible providers, thereby facilitating the delivery of coordinated and integrated care.

FOUNDATIONAL STEPS

- Based on a comprehensive, multi-disciplinary, biopsychosocial assessment of the patient’s strengths, goals, priorities and needs, create a plan of care with the patient (along with any care partner the patient designates) that includes:
 - the patient’s care goals, action steps, time frame and proposed interventions, including how to address documented challenges;
 - how the patient’s clinical—including behavioral health – and non-clinical (e.g., Medicaid, housing, financial) health care needs and services will be coordinated and integrated;
 - the care and support services that are crucial to the patient’s independence, including those the patient receives (i.e., the service, who provides it, where and when), those the patient needs, and those to which the patient is referred;
 - incorporation of any information that has been shared by a pediatrician who is transferring the care of his or her patient to an adult primary care provider (see When Pediatricians Transfer Patients to an Adult PCP); and
 - full access (electronically and on paper) for the patient to the initial plan, as well as to any subsequent changes or updates.

¹⁰The Disability Competent Care Self-Assessment Tool, from which much of the material in this section was drawn, was developed by the Institute for Healthcare Improvement Learning Collaborative (of which ICS is a member, along with the Community Health Partnership of Wisconsin and Community Medical Group/Commonwealth Care Alliance of Massachusetts) as “an aspirational model of disability-competent care.” It covers many aspects of care management, including the relationship of care management to primary care. For more, go to <https://www.cms.gov/medicare-medicare-coordination/medicare-and-medicare-coordination/medicare-medicare-coordination-office/downloads/dccassessmenttool.pdf>

- Determine methods and resources to offer basic patient education, including:
 - providing orientation to the practice and primary care, including provider and patient responsibilities and expectations;
 - providing each patient (as well as his or her caregiver or personal aide, if patient requests) with individual disease/condition education that includes management, prevention and risks, and ensuring that the education is tailored to the patient's health literacy level; and
 - educating each patient about their medications – what they are taking, why, the required schedule, potential side effects and interactions with their particular disability, and who/when to call with questions.
- Begin to build a network of accessible providers to whom you can refer your patients and who will begin to refer patients to you.
 - Start with the patient's current network of health care providers. Frequently, you will find that patients have already built a network of specialists and other providers who address their needs related to the disability, as well as secondary conditions. With the providers and the patient, you can ensure that the patient receives holistic, full body support and coordinated care.
 - Establish relationships with organizations focused on specific disabilities common among your patients (e.g., MS Society, United Cerebral Palsy), which can provide lists of participating clinicians, clinical support, alerts to new developments, and support services. (See Appendix E.)
 - Engage with community organizations of people with disabilities such as your local Independent Living Center, whose staff and volunteers have knowledge of and can facilitate access to existing resources.
 - Identify and include in your network providers of long-term services and supports (LTSS), which are fundamental to making sure that adults with physical disabilities can live independently in the community. LTSS provide help, paid and unpaid, with activities of daily living (e.g., eating, bathing, dressing) and instrumental activities of daily living (e.g., preparing meals, managing medication, housekeeping).
 - LTSS include but are not limited to: adult and social day care; home care (personal care aides, home health aides, assistance provided by a family caregiver); safety/accessibility assessments of home environments for modifications (lifts, transfer boards, bathroom grab bars); skilled nursing and in-home skilled therapy such as PT, OT, respiratory and speech; respiratory equipment; hospitalization prevention services (e.g., at-home infusion therapy); nursing home care; hospice services; nutrition services; community pharmacists; and transportation.
 - Include in your network durable medical equipment vendors and mobility equipment specialists who handle wheelchairs, scooters, walkers, prosthetic/orthotic devices, and so on, and who provide Complex Rehab Technology (CRT) sales and service—again, beginning with the providers already serving your patients.
 - Ensure that diagnostic imaging referral sites are accessible (e.g., a mammography machine that lowers to accommodate a woman in a seated position; transfer boards or stretchers that ease transfer of a patient from a wheelchair to the fixed-height table for an MRI, X-ray, CT scan).
 - Ensure that patients know what resources are available for care outside of office hours—a 24-hour crisis hotline, an accessible urgent care center, a covering physician or nurse, the local emergency room, etc.
 - Assist patients, if necessary, in making appointments at referral sites and follow up with referral sources, including using electronic medical records software to create and submit reports to other providers regarding the patient's status and changes in care.

ADVANCED STEPS

- Conduct or refer your patients out for:
 - support groups (e.g., for women; men; those with a particular disease or disability; the newly injured; those with congenital conditions or conditions developed in childhood);
 - peer support programs (e.g., for SCI patients, MS patients); and
 - group education sessions (e.g., Disability Rights and How to Protect Them; Love, Intimacy, and Disability; Women with Disabilities and Breast Cancer). (See Appendix F for suggested resources.)
- Ensure that people with physical disabilities appear in your marketing materials and campaigns, and that those materials tend to literacy levels and cultural appropriateness.
- Use your website to promote your services for adults with physical disabilities, including links to organizations that will be of use to your patients.
- Hold webinars on subjects of interest to your patients, including featuring your own knowledgeable, experienced staff.
- Invite speakers from disability advocacy or disability-related organizations to speak at your events.



Carmelo Gonzalez
ICS member

Advocating for Change

In the process of providing care to adults with physical disabilities, primary care providers will inevitably come up against regulations and public policies that interfere with the provision of care. They include, for example, insufficient insurance reimbursement for longer patient visits or for the additional staff or resources required to care for some adults with physical disabilities. They include the refusal by some insurers to pay for a customized motorized wheelchair that is essential to a patient's being able to safely work, travel, and live his or her most active, independent life. They also include the refusal of some providers to use positioning aides such as Velcro straps to stabilize a woman's arm so that she can have a mammogram, mistakenly believing that such aides constitute legally prohibited restraint.

Counterproductive policies and regulations need to be identified and documented in order for disability rights activists to have the evidence they need to advocate for change. You can make a significant contribution by:

- documenting what diagnoses and disabilities you are seeing in your patients that necessitate longer appointment times, additional staff and any other additional resources;
- documenting the impact of barriers to care that you see in your patients (e.g., the development of a wound in the absence of a preventive support service or the inability to work due to not having a motorized wheelchair);
- documenting the insurance/facility/other regulations that impede your ability to provide care efficiently and cost effectively to your patients with physical disabilities; and
- sharing your findings with disability rights advocates, who can use them to support crucial initiatives for policy change.

Finally, you can help adults with physical disabilities to find accessible providers by being sure to include your office's accessibility in online profiles of your practice. You can also inform your patients that they can use online sites (such as [Yelp.com](https://www.yelp.com) and AXS Map at <https://www.axsmap.com>) to help them to check the accessibility of community resources, from stores to restaurants to health care providers, and to share their own experiences with providers concerning accessibility in the comments sections of sites such as [ZocDoc.com](https://www.zocdoc.com) (<https://www.zocdoc.com>) [HealthGrades.com](http://www.healthgrades.com) (<http://www.healthgrades.com>) and [Vitals](http://www.vitals.com) (<http://www.vitals.com>).

Conclusion

As we said at the outset, the most important action a primary care provider can take regarding improving the health and lives of adults with physical disabilities is to commit to increasing access to care within his or her own practice. By taking any of the steps outlined in this Blueprint, you will be achieving that goal and helping to develop this important field. The field will be further advanced as individual health care practitioners use this Blueprint to expand their practice with aspirations of one day becoming a Center of Excellence in Primary Care for Adults with Physical Disabilities, working on an ongoing basis to achieve that goal.

Beyond that, our vision is that one day, an adult in a wheelchair, with spasticity or an uneven gait, using a respirator, or evidencing any other aspect of a physical disability will no longer inspire dread in ill-prepared health care providers. Instead, he or she will be welcomed by providers who are skilled, knowledgeable, experienced, and comfortable offering care.

Though we're not there yet, you have the ability to help change this picture, to help change individual people's lives. You may only be able to care for a few adults with physical disabilities a week, a few more a month, perhaps a few dozen a year. But change must begin somewhere. It is our hope that, after reading this document, it will begin with you.

APPENDIX A

Blueprint Advisory Committee Members

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Anna Martinez, Coordinator, Women's Health Program

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APPENDIX B

Sample Accessibility Survey Form*

Facility Name _____

Completed By _____

Date _____

Facility entrance

Is there an accessible entrance to the facility? Yes ☐ No ☐ N/A ☐

If the accessible entrance to the facility is separate from the main entrance, are there visible and clear signs directing people to the accessible entrance such as the sign to the right or a similar sign?

Yes ☐ No ☐ N/A ☐

What type of automatic door opener does the door at the accessible entrance have?

- ☐ Pressure mat on the ground inside and outside of the door that opens the door when walked or rolled on
- ☐ Push button automatic door opener in working condition
- ☐ Visual Sensor
- ☐ None



Is there a curb-cut to a sidewalk that leads to the entrance to the building?

Yes ☐ No ☐ N/A ☐

If there are steps to the building entrance, are there handrails that people who use canes or who are unsteady can use?

Yes ☐ No ☐ N/A ☐

If there are steps to the building entrance, is there also a ramp?

Yes ☐ No ☐ N/A ☐

Some doors have thresholds at the bottom like the one pictured here. If there is a threshold at the door, use a tape measure and answer the following questions:

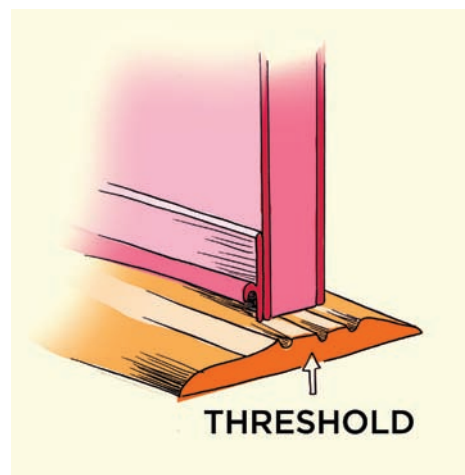
- ☐ The door has no threshold.
- ☐ There is a threshold that is vertical to the floor.

Yes ☐ No ☐ N/A ☐

Is the vertical threshold $\frac{1}{4}$ inch high or less?

Yes ☐ No ☐ N/A ☐

There is a threshold that is beveled (rounded).



Ramp accessibility

If there is a ramp to the building entrance, complete the following section.

Does the ramp have flat landings (no slope) at the top and the bottom as pictured here.

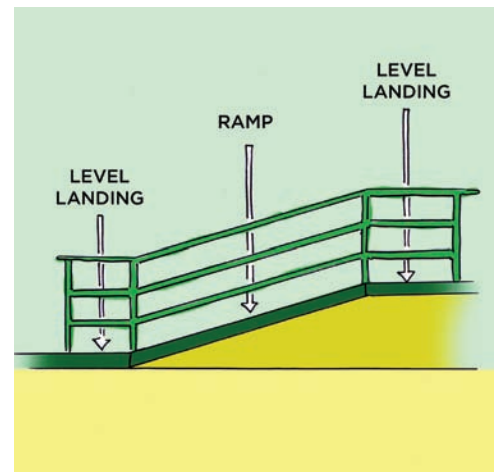
Yes ☐ No ☐ N/A ☐

Are the landing(s) at least 5 feet long and the width of the ramp?

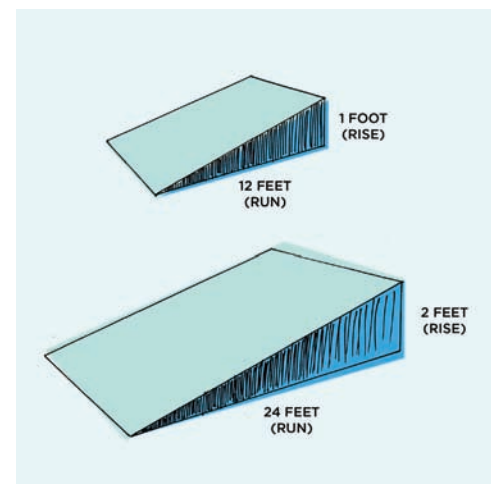
Yes ☐ No ☐ N/A ☐

If the ramp is segmented (with one or more turns), is there a landing between the segments that is at least 5 feet long and the width of the ramp?

Yes ☐ No ☐ N/A ☐



Ramps must have a maximum steepness—one inch of “rise” (height) to every foot of “run” (length) as in the diagram on the right.



To find out if the ramp meets this requirement, do the following:

Measure how high it is from the bottom of the ramp to the top (the vertical rise). _____ inches

Measure how long the ramp is. _____ inches

Yes ☐ No ☐ N/A ☐

If there is more than one inch of rise (height) for every 12 inches of run (length), the ramp is too steep. Is it?

Yes ☐ No ☐ N/A ☐

Are there handrails along the ramp, no more than 48 inches from the surface of the ramp?

Elevator accessibility

Do the elevator doors remain open a minimum of 5 seconds?

Yes ☐ No ☐ N/A ☐

Are the elevator doors a minimum of 36 inches wide when fully opened?

Yes ☐ No ☐ N/A ☐

Restroom guidelines

- Is the doorway to the restroom at least 36 inches wide? Yes ☐ No ☐ N/A ☐
- Can the water in the sink be turned on and off with one hand or a closed fist? Yes ☐ No ☐ N/A ☐
- Can the soap dispenser be activated by a person who uses a closed fist? Yes ☐ No ☐ N/A ☐
- Is the top of the sink counter a maximum of 34 inches from the floor surface? Yes ☐ No ☐ N/A ☐
- Is the sink counter a minimum of 17 inches from the wall to the front of the counter? Yes ☐ No ☐ N/A ☐
- Is there at least 27 inches of “knee space” below the sink so people using wheelchairs can fit their knees underneath? Yes ☐ No ☐ N/A ☐

Multi-user stalls

- If there is an accessible stall in which the toilet is mounted on the floor, is there a minimum of 59 inches between the back wall and the front wall of the stall? Yes ☐ No ☐ N/A ☐
- If the facility has an accessible stall in which the toilet is mounted on the wall, is there a minimum of 56 inches between the back wall and the front wall of the stall? Yes ☐ No ☐ N/A ☐
- Is the width of the accessible stall at least 60 inches so that someone can transfer from a wheelchair or scooter inside of the stall? Yes ☐ No ☐ N/A ☐
- Is the doorway to the stall at least 36 inches wide?
- Is the top of the toilet seat between 17 inches and 19 inches from the surface of the floor? Yes ☐ No ☐ N/A ☐
- Is the flush control on the open side of the toilet, opposite from the wall? Yes ☐ No ☐ N/A ☐
- Is there a horizontal grab bar on the side of the toilet that is 36 inches above the surface of the floor? Yes ☐ No ☐ N/A ☐
- Is there a vertical grab bar that a person sitting on the toilet can use to help lift them? Yes ☐ No ☐ N/A ☐
- Is there a grab bar behind the toilet on the wall? Yes ☐ No ☐ N/A ☐

Single-user stalls

- Does the entry door swing out with at least a 32 inches clear opening, including any protruding hinges, etc.?
Yes ☐ No ☐ N/A ☐
- Is there a 5-foot turning area in front of the commode and sink (radius at least 2.5 feet)?
Yes ☐ No ☐ N/A ☐
- Is the top of the toilet seat between 17 inches and 19 inches from the surface of the floor?
Yes ☐ No ☐ N/A ☐
- Is the flush control on the open side of the toilet, opposite from the wall?
Yes ☐ No ☐ N/A ☐
- Is there a horizontal grab bar on the side of the toilet that is 36 inches above the surface of the floor?
Yes ☐ No ☐ N/A ☐
- Is there a vertical grab bar that a person sitting on the toilet can use to help lift them?
Yes ☐ No ☐ N/A ☐
- Is there a grab bar behind the toilet on the wall?
Yes ☐ No ☐ N/A ☐

Outpatient reception area guidelines

- Is there an intake waiting area?
Yes ☐ No ☐ N/A ☐
- Is there a separate waiting area?
Yes ☐ No ☐ N/A ☐
- Is the opening in the main entry door to the reception/waiting area at least 36 inches wide?
Yes ☐ No ☐ N/A ☐
- Are the tops of any work surfaces such as countertops, etc.:
Yes ☐ No ☐ N/A ☐ A minimum of 28 inches from the floor?
Yes ☐ No ☐ N/A ☐ A maximum of 34 inches from the floor?
- Are there open floor spaces in the seating/waiting area where people with wheelchairs, scooters, strollers, or service animals can easily wait?
Yes ☐ No ☐ N/A ☐
- Is there an area where a power wheelchair can be plugged in to charge?
Yes ☐ No ☐ N/A ☐
- Is there at least 27 inches of “knee space” below work surfaces such as reception desks, telephone counters, etc. so people using wheelchairs can fit them underneath?
Yes ☐ No ☐ N/A ☐
- Are there signs posted in the waiting room directing people to the accessible restrooms if they are not clearly visible from the waiting room?
Yes ☐ No ☐ N/A ☐

Exam room guidelines

- Does the entry door swing out with at least a 32-inch clear opening, including any protruding hinges, etc.? Yes ☐ No ☐ N/A ☐
- Is there a 5-foot turning area in the exam room (radius at least 2.5 feet)? Yes ☐ No ☐ N/A ☐
- Is there a wheelchair accessible weight scale in the exam room? Yes ☐ No ☐ N/A ☐
- Does the room have an accessible exam table? Yes ☐ No ☐ N/A ☐
- Yes ☐ No ☐ N/A ☐ Can the table be lowered to at least 17 inches?
- If not, how low can the table go? _____ inches
- Yes ☐ No ☐ N/A ☐ Are there side rails?
- Yes ☐ No ☐ N/A ☐ Is there a safety belt?
- Yes ☐ No ☐ N/A ☐ Are there padded, adjustable stirrups (for women's health exams)?
- Yes ☐ No ☐ N/A ☐ Can the table adjust to a sitting position?
- Yes ☐ No ☐ N/A ☐ Is there a weight limit on the exam table?
- Yes ☐ No ☐ N/A ☐ Is there a patient transfer (Hoyer lift) in the room?
- Yes ☐ No ☐ N/A ☐ If no: Is there one in the clinic area?
- Yes ☐ No ☐ N/A ☐ If yes, does staff know where it is?
- Is clinical staff trained to safely transfer a person from a wheelchair to an exam table and back? Yes ☐ No ☐ N/A ☐
- Yes ☐ No ☐ N/A ☐ Using a lift?
- Yes ☐ No ☐ N/A ☐ Using a sliding transfer board?
- Yes ☐ No ☐ N/A ☐ Lifting or standing pivot transfer?

Dressing room guidelines

- Is there a dressing room that is separate from the exam room? Yes ☐ No ☐ N/A ☐
- Is the room a minimum of 5 feet by 6 feet? Yes ☐ No ☐ N/A ☐
- Does the doorway to the dressing or changing room provide at least 36 inches of clear space to go through, including hinges that might protrude in the door opening? Yes ☐ No ☐ N/A ☐
- Is there a changing bench with a top surface between 17 inches and 19 inches from the floor? Yes ☐ No ☐ N/A ☐
- Is there back support for the bench? Yes ☐ No ☐ N/A ☐

Is there a 5-foot turning area of clear floor space next to or in front of the bench (radius of at least 2.5 feet)? Yes ☐ No ☐ N/A ☐

Is there a horizontal grab bar located 36 inches above and parallel to the floor for use by someone sitting on the bench? Yes ☐ No ☐ N/A ☐

Is there a vertical grab bar that a person sitting on the bench can use to help lift them off the bench? Yes ☐ No ☐ N/A ☐

In lieu of an accessible changing area, are patients able to change somewhere else? Yes ☐ No ☐ N/A ☐

Is staff trained and able to help individuals with disabilities change in and out of clothing if necessary? Yes ☐ No ☐ N/A ☐

Mammography suite

Does the mammography suite have a separate waiting area? Yes ☐ No ☐ N/A ☐

Yes ☐ No ☐ N/A ☐ If so, are there open floor spaces in the seating area where people with wheelchairs, scooters, strollers, or service animals can easily wait?

Is the opening in the mammography waiting area at least 36 inches wide? Yes ☐ No ☐ N/A ☐

Are the tops of any work surfaces such as countertops, etc.: Yes ☐ No ☐ N/A ☐

Yes ☐ No ☐ N/A ☐ a minimum of 28 inches from the floor?

Yes ☐ No ☐ N/A ☐ a maximum of 34 inches from the floor?

Are there open floor spaces in the seating area where people with wheelchairs, scooters, strollers, or service animals can easily wait? Yes ☐ No ☐ N/A ☐

Is there an area where a power wheelchair can be plugged in to charge? Yes ☐ No ☐ N/A ☐

Is there at least 27 inches of “knee space” below work surfaces such as reception desks, telephone counters, etc. so people using wheelchairs can fit them underneath? Yes ☐ No ☐ N/A ☐

Are there signs posted in the waiting room directing people to the accessible restrooms if they are not clearly visible from the waiting room? Yes ☐ No ☐ N/A ☐

Mammography room

Is there a pathway at least 36 inches wide leading to the mammography machine that can be used by someone in a wheelchair? Yes ☐ No ☐ N/A ☐

Does the bucky or imaging plate lower to 24 inches above the floor, allowing a person to remain seated in their wheelchair while the mammogram is performed? Yes ☐ No ☐ N/A ☐

Is there a 5-foot turning area in front of the machine (radius at least 2.5 feet)? Yes ☐ No ☐ N/A ☐

Is there a mammogram chair in the room or quickly accessible to the technician? Yes ☐ No ☐ N/A ☐

Is there a separate bathroom for the sonogram room? Yes ☐ No ☐ N/A ☐

Yes ☐ No ☐ N/A ☐ If yes, is it accessible?

What height does the sonogram table lower to? _____ Yes ☐ No ☐ N/A ☐

Yes ☐ No ☐ N/A ☐ Is there a weight limit on the sonogram table?

Yes ☐ No ☐ N/A ☐ Can the table adjust to a sitting position?

Is there a patient transfer lift in the room? Yes ☐ No ☐ N/A ☐

Yes ☐ No ☐ N/A ☐ If no: Is there one in the clinic area?

Yes ☐ No ☐ N/A ☐ If yes, does staff know where it is?

Is clinical staff trained to safely transfer a person from a wheelchair to an exam table and back? Yes ☐ No ☐ N/A ☐

Yes ☐ No ☐ N/A ☐ Using a lift?

Yes ☐ No ☐ N/A ☐ Using a sliding transfer board?

Yes ☐ No ☐ N/A ☐ Lifting or standing pivot transfer?

Notes: _____

APPENDIX C

Resources for Facilities and Equipment Accessibility

ADA National Network—Information, Guidance and Training on the ADA, Fact Sheet for Health Care Providers regarding Laws and Technical Criteria for Increasing Accessibility of Medical Diagnostic Equipment. <https://adata.org/factsheet/accessible-medical-diagnostic-equipment>

ADA Standards for Accessible Design, US Department of Justice Civil Rights Division. <https://www.ada.gov/regs2010/2010ADASTandards/2010ADASTandards.htm>. The Department also provides an ADA technical assistance hotline: (800) 514-0301 (voice); (800) 514-0383 (TTY).

Access to Medical Care for Individuals with Mobility Disabilities, Guidelines from the US Department of Justice Civil Rights Division. Includes features of accessible exam rooms, accessible medical equipment, and training. http://www.ada.gov/medcare_mobility_ta/medcare_ta.pdf

Advancing Equal Access to Diagnostic Services: Recommendations on Standards for the Design of Medical Diagnostic Equipment for Adults with Disabilities, United States Access Board, Final Report of the Medical Diagnostic Equipment Accessibility Standards Advisory Committee, December 6th, 2013. <http://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/advisory-committee-final-report/executive-summary>

American Association on Health and Disability, Mammography Accessibility Facility Survey. <http://www.aahd.us/wp-content/uploads/2012/03/MammoFacilitySurvey2009-10.pdf>

Americans with Disabilities Act Checklist for Readily Achievable Barrier Removal. Includes detailed regulations for existing facilities. <http://www.ada.gov/racheck.pdf>

Breaking Down Barriers, Breaking the Silence: Making Health Care Accessible for Women with Disabilities, Independence Care System and New York Lawyers for the Public Interest, October, 2012. <http://www.icsny.org/sitemanagement/wp-content/uploads/2012/10/BreakingBarriers.pdf>

Northeast ADA Center, Cornell University. One of ten regionally-based ADA Centers funded by the National Institute for Disability and Rehabilitation Research; provides information, referrals, resources and training on equal access for individuals with disabilities and on the Americans with Disabilities Act. <http://www.northeastada.org/>

Removing Barriers to Health Care: A Guide for Health Professionals, Center for Universal Design and the North Carolina Office on Disability and Health. http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/NCODH_RemovingBarriersToHealthcare.pdf

Tax Credits for Businesses

Deductions (section 190, IRC), see Publication 535 (#7, barrier removal) at www.irs.gov/publications/p535/index.html

Disabled Access Credit (section 44, Internal Revenue Code: Form 8836) at www.irs.gov/pub/irs-pdf/f8826.pdf

Tax Benefits for Businesses Who Have Employees with Disabilities <https://www.irs.gov/businesses/small-businesses-self-employed/tax-benefits-for-businesses-who-have-employees-with-disabilities>

Tax Incentives for Improving Accessibility, ADA Fact Sheet <http://www.ada.gov/archive/taxpack.pdf>

APPENDIX D

Resources for Disability Sensitivity and Awareness Training

Access to Medical Care: Adults with Physical Disabilities, World Institute on Disability's 22-minute DVD for physicians, dentists, nurses, and other medical staff, with accompanying training curriculum (charge for the DVD; curriculum comes with DVD, and is also available online). <https://wid.org/tag/doctors/>

Approaches to Training Health Care Providers on Working with Patients with Disabilities, Association of University Centers on Disability & Alliance for Disability in Health Education. Susan M. Haverkamp, PhD, Ohio State University Nisonger Center; Kenneth Robey, PhD, Matheny Medical and Educational Center, and University of Medicine and Dentistry of New Jersey; Suzanne Smeltzer, EdD, RN, FAAN, Villanova University College of Nursing. <http://fndusa.org/wp-content/uploads/2015/05/Approaches-to-Training-Healthcare-Providers.pdf>

CDC Train, Access to over 1300 courses developed by the Centers for Disease Control and Prevention (CDC) programs, grantees, and other funded partners, some with disability focus for health professionals; approved and verified by CDC. <https://cdc.train.org/DesktopShell.aspx>

A Curriculum to Teach Medical Students to Care for People with Disabilities: Development and Initial Implementation. Symons AB, McGuigan D, Akl EA. Supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration Pre-Doctoral Training in Primary Care Grant. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2809044/>

Disability Sensitivity and Awareness Training for Women's Health Care Providers, ICS Training Manual for Facilitators. Independence Care System. A step-by-step two-hour training session on disability sensitivity and awareness, which can be adapted to other health care providers, not only those working in women's health. Available for purchase; call (718) 907-1614 or email whp@icsny.org.

Tools to Empower Clinicians and Women with Disabilities to Interact Effectively, Association of Maternal and Child Health Programs. <http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/WomensHealthDisability/Pages/CliniciansandWomenInteractions.aspx>

APPENDIX E

Resources for Clinical Expertise

Professional Organizations for Specific Disabilities

Cerebral Palsy Foundation – Offers online resources (e.g., regarding pain in CP, sensory therapies for CP, constraint-induced movement therapy); funds research and educational activities related to cause, cure and evidence-based care; and operates collaborative networks of medical institutions and innovative thinkers focused on critical advances in care. <http://yourcpf.org/>

National Multiple Sclerosis Society – Offers online resources as well as operating the Partners in MS Care Program, which encourages strong partnerships between clinicians and the Society. <http://www.nationalmssociety.org/> See also the Consortium of Multiple Sclerosis Centers. <http://www.mscares.org/>

National Parkinson's Foundation – Educates doctors and nurses on caring for patients with Parkinson's; focuses on training health care professionals in best practices, providing the latest, quality information and increasing access to free educational tools. <http://www.parkinson.org/expert-care-research/professional-training>

Paralyzed Veterans of America – Provides specialized information accessible for diverse audiences, from clinical practice guidelines for health care specialists to self-help guides for people with disabilities. http://www.pva.org/site/c.ajIRK9NJLcJ2E/b.7516843/k.6FC/Paralyzed_Veterans_of_America_Publications.htm

Post-Polio Health International – An online community of persons living post-polio. The site offers a tab for health care providers, referencing information that is useful when working with a person post-polio. <http://www.post-polio.org/>

Spina Bifida Association – Offers online resources covering, e.g., how to treat specific symptoms; what constitutes an emergency and what treatment is required; osteoporosis and how to manage the risk of fractures; and a transition worksheet for pediatricians to provide information to a patient's adult provider. In process of forming a Spina Bifida Collaborative Care Network. <http://spinabifidaassociation.org/>

United Spinal Association – Enhances the quality of life of all people living with a spinal cord injury or disease (SCI/D), offering programs and services that provide support and information to loved ones, care providers and professionals. <http://www.unitedspinal.org/>

General Clinical Resources

Gynecological Considerations in Treating Women with Physical Disabilities, power point from Baylor College of Medicine, Center for Research on Women with Disabilities, available here: <https://www.bcm.edu/research/centers/research-on-women-with-disabilities/topics/health-care/medical-professionals-knowledge>

International Classification of Functioning, Disability and Health Checklist, a practical tool to gather information about an individual's functioning and disability, from the World Health Organization. Aims to help practitioners capture changes in body functions and structures by assessing the impact of those changes on what a person can do in a standard environment (their level of capacity) and what they actually do in their usual environment (their level of performance). Shifts emphasis from a person's disability to their level of health. <http://www.who.int/classifications/icf/icfchecklist.pdf?ua=1>

Primary Care Providers and Chronic Spinal Cord Injury: What Patients' PCPs Need to Know, Paralyzed Veterans of America, H. Keels S. Jorn, MD. Online presentation that covers mechanisms in which spinal cord injury can alter the presenting signs and symptoms of common medical conditions seen in primary care; educational opportunities for primary care providers in the care of chronic spinal cord injured patients; and resources that can enhance primary care for patients with chronic spinal cord injury. http://www.pva.org/atf/cf/%7BCA2A0FFB-6859-4BC1-BC96-6B57F57F0391%7D/Summit2012_0830Jorn%20130.pdf

Providing Disability-Competent Primary Care, Resources for Integrated Care, part of webinar series facilitated by the CMS Medicare-Medicaid Corporation Office. https://www.resourcesforintegratedcare.com/Physical_Disabilities/Care_Management/Webinar/Providing_Disability_Competent_Primary_Care/webinar4

Reproductive Health Care for Women with Disabilities. An interactive narrated tutorial with six modules from the American College of Obstetricians and Gynecologists, which has an interactive site for clinicians serving women with disabilities. This free slide presentation is for clinicians caring for women with physical, developmental or sensory disabilities, including SCI, spina bifida, MS, and Cerebral Palsy. CME credits offered for each module; tests included. Link at <http://www.acog.org/About-ACOG/ACOG-Departments/Women-with-Disabilities/Interactive-site-for-clinicians-serving-women-with-disabilities>

Toolbox: Improving the Receipt of Clinical Preventive Services among Women with Disabilities. Association of Maternal and Child Health Programs. <http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/WomensHealthDisability/Pages/default.aspx>

UpToDate (www.uptodate.com/home) is an evidence-based, physician-authored clinical decision support resource, which clinicians use to help make point-of-care decisions. Some 6,000 physician authors, editors, and peer reviewers synthesize recent medical information into evidence-based recommendations. Clinical content covers 22 specialties, 10,500 topic reviews and 1,500 patient education topics. Used by one million clinicians in 174 countries and almost 90 percent of US academic medical centers; has been the subject of 60 research studies, including a 2011 Harvard study that found using the service to be “associated with improved patient care and hospital performance.” Subscription fees vary.

Veterans Administration Patient Aligned Care Team (PACT). Provides veterans with primary care that is patient-centered, data driven, continuously improving, team-based, accessible, timely, comprehensive, coordinated, and provides continuity of care over time. <http://www.va.gov/health/services/primarycare/pact/index.asp>

APPENDIX F

Resources for Patient Education

Independence Care System – Publishes Tip Sheets for consumers, in multiple languages, on wheelchair maintenance, fall prevention, prevention of pressure ulcers, the health care rights to women with breast cancer, caring for a loved one with dementia, and how to have a good relationship with a home care worker. Available free of charge at <http://www.icsny.org/pubsvids>

National Standards for Diabetes Self-Management Education and Support, which were designed to assist diabetes educators in providing evidence-based education and self-management support. The Standards are applicable to educators in solo practice as well as those in large multicenter programs. <http://care.diabetesjournals.org/content/35/11/2393.extract>

Paralyzed Veterans of America – Has a library of materials for education regarding life after a spinal cord injury; the materials are developed for both patient and professional audiences. http://www.pva.org/site/c.ajIRK9NJLcJ2E/b.6305817/k.3A08/Spinal_Cord_Research_Education.htm

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Independence
care system

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