Supporting documents for:

IMPROVING ACCESS AND CARE FOR PATIENTS WITH PHYSICAL DISABILITIES

This PDF file contains the following three articles:


How usable are your health care services and facilities to people with disabilities?

Can you weigh people who can’t stand on the scale? Can you communicate with patients with hearing disabilities? Is it easy for your patients to move freely throughout your facility?

This booklet provides guidelines and recommendations to help health care professionals ensure equal use of the facility and services by all their patients. The information in this guide gives health care providers a better understanding of how to improve not only the physical environment, but also their personal interactions with patients with disabilities. There is also a review of some of the design standards established through state and federal laws, such as the Americans with Disabilities Act (ADA), that health care professionals need to know.

This guide encourages health care professionals to go beyond the minimum requirements set by law to make facilities and services universally usable to the greatest extent possible. By meeting the needs of people with disabilities, you will also be providing enhanced facilities and services to all your patients.
Scope of the Problem

People with disabilities represent a large and growing sector of the population that needs health care services. While over 54 million Americans have been identified as being disabled, the true number of people with a disability is unknown. At some point, almost everyone experiences a disability as they age.

However, many people with disabilities do not seek out or obtain quality health care. Often, health care facilities are not accessible or do not have the equipment needed to serve people with disabilities. Also, people are often embarrassed because their disability requires them to obtain additional assistance from the staff, requiring them to surrender some of their independence. Sometimes, staff may not know how to assist a person with a disability, causing frustration for both the patient and the staff member. As a result, some people with disabilities only pursue medical attention for emergency or acute conditions, making primary and preventive health care services low priorities.

From the providers’ perspective, limitations in the physical environment, such as the lack of appropriate equipment, may cause doctors and other professionals to forgo, omit, or not recommend procedures or portions of procedures for people with disabilities that would otherwise be commonplace. Increasing accessibility at health care facilities will encourage more people to seek out services, thus increasing client bases as well as the general health of individuals with disabilities.

Providing Universal Access

Universal access or universal design is a concept, that, when applied to environments, ensures that facilities, products, and services are usable by all people. Everyone, regardless of ability, benefits from universal design. Wide doors make moving equipment and furniture easier for everyone. Spacious toilet rooms provide space for wheelchair users but also accommodate parents with strollers or several children. A place to sit while transacting
Business is good for anyone when they are tired, not feeling well, or pregnant. Recommended universal design features, such as power door operators and adjustable-height examining and treatment tables, work well for everyone including children and older adults.

Some people-accommodating features also add to the value of the property, create a more interactive environment, relieve staff of unnecessary extra work, and help maintain a comfortable place to work and visit. Going beyond the minimum requirements makes your facility more usable for all patients. Following is a checklist of ways to improve usability and broaden participation in health care.

**Recommended Universal Design Features**

- ✔ weather protection at entrance doors
- ✔ power door operators at interior and exterior entrances
- ✔ spaces left open but dispersed in waiting areas where wheelchair users can sit out of traffic lanes but with other people
- ✔ chairs for use by people who cannot stand while transacting business
- ✔ chairs that can be set at different heights for use by children, adults and older people, some equipped with arm rests for those who need assistance rising to their feet
- ✔ scales that allow people with difficulty standing to hold on, and one that allows people to be weighed while sitting in a wheelchair
- ✔ motorized, adjustable-height treatment and examining tables and chairs
- ✔ mammography machines that can be used on a woman in a seated position
- ✔ a portable, amplified communication system or device with volume control at service desks and treatment spaces for people who are hard of hearing
- ✔ more than one accessible toilet and dressing room, some left-handed and some right-handed
- ✔ a TTY for use by people who are deaf to make phone calls from health care facilities
- ✔ staff awareness and training in using the National Telephone Relay System
- ✔ awareness and sensitivity training for all staff and professional personnel on interacting with people with disabilities
Creating Accessible Environments and Services

Creating accessible health care environments does not have to be expensive. In new construction, accessibility features generally do not increase costs. In fact, even in existing facilities, necessary modifications are not always expensive. And there may be alternative devices or services that can be used as interim solutions when needed changes may not be readily achievable.

Following are some guidelines for creating and modifying health care facilities to be accessible to people with disabilities. By integrating these into your buildings and services, you can provide universally usable environments beneficial to all your consumers.

Learn and Adhere to Codes and Laws Regarding Accessibility

Many different local and state building codes, as well as civil rights laws, address accessibility. When building, buying, remodeling or furnishing facilities, health care providers are responsible for ensuring their facilities adhere to all accessibility requirements. Because there is no plan review or approval and permit process for accessibility requirements, health care practitioners may not know their obligations and liability. One must not assume that contractors are aware of and will address all required obligations. Following are some of the laws and codes you need to become familiar with to ensure you are in compliance with accessibility regulations.

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal law that prohibits discrimination against, or segregation of, people with disabilities in all activities, programs, or services. While the ADA is similar to and patterned after other civil rights laws, it differs in that it also has a major impact on the design, construction, and operation of buildings and facilities, transportation vehicles, and many of the products that go into them.
The regulations for implementing the ADA include a broad set of building design specifications for new construction, additions, and remodeling called the *Americans with Disabilities Act Standards for Accessible Design*. Due to their importance in the lives of people with disabilities, facilities providing health care are held to an even higher standard than other businesses. For example, in new construction, elevators waived for very small, two-story office buildings must be provided in health care office buildings of any size. The *ADA Standards* are being adopted and used as part of state, regional, and national building codes where they are becoming part of common practice for review, approval, and construction permits. Even without local adoption and enforcement, the regulations are mandatory and individuals may file complaints for non-compliance with owners, managers, and the U.S. Department of Justice.

**Rehabilitation Act of 1973**

Section 504 of the federal Rehabilitation Act of 1973 requires that any program or service receiving federal financial assistance, either directly or indirectly, be accessible to everyone. Most public services fall in this category, including health care facilities. Meeting the requirements of Section 504 can be accomplished by changing policies, providing services such as sign-language interpreters, installing text telephones for deaf clients, or relocating the program to an accessible facility.

**State and Local Building Codes**

Most states have building codes or other regulations that specify and require accessibility for people with disabilities in building design and construction. These vary in scope, detail, and enforcement. Some are local, city or county codes instead of statewide. Some states also have civil rights laws prohibiting discriminatory practices.

NOTE:

The *ADA Standards for Accessible Design*, state, and/or local codes contain technical dimensions governing the design of specific features. Be certain you or your architect refer to all applicable compliance documents.
The following chart highlights some of the key ADA requirements that should not be overlooked. The illustrations that follow combine Universal Design Features with requirements of the ADA to depict environments that are safer and easier for all visitors, patients, and staff to use.

**Selected ADA requirements for health care providers**

- accessible parking spaces close to entrances
- accessible front entrance with ramp and curb cut at appropriate grades and surfaces
- interior and exterior doors that are wide and easy to open
- accessible route throughout the facility connecting all accessible features and service areas
- clear floor space so people, even those using wheelchairs, can get close to and reach all controls and other features
- controls, storage facilities and amenities such as magazine and literature racks for wheelchair users
- low counters, service windows or receptionist stations for transactions with short or seated people
- desk-height writing surfaces with knee space for use by wheelchair users and others who cannot stand while transacting business
- accessible toilet and dressing rooms large enough for a person using a wheelchair to navigate
- audible and visual alarm systems
- qualified sign language interpreters for communication with people who are deaf
- large printout capability of key papers and documents for people with low vision
- raised lettering and Braille on selected signs such as room and elevator controls

**Accessible Parking Spaces**

- standard width parking space
- sign with the international access symbol designating space for accessible parking
- sign with access symbol and text that reads “van-accessible”
- 60” wide access aisle shared by two parking spaces
- 96” wide access aisle for “van-accessible” parking
visible and easily understood signage to indicate entrance, parking, etc.

detectable warnings at curbless walks that cross vehicle traffic lanes cue people with vision disabilities of possible hazards

Entrance incorporates an accessible passenger loading zone with adequate room to get on and off bus and van lifts

- accessible parking near entrance
- smooth transitions from entrance to loading areas and walks
- covered entrance for weather protection

Health Care Facility Entrance
Additional Features

- Large furniture pieces combined with easy-to-move single chairs allow multiple seating arrangements.
- Adequate space around door, including pull space to side, for maneuvering.
- Open floor areas for wheelchair, scooter, or baby carriages, dispersed throughout seating.

Lobby and Reception Area

- Dual height water fountains serve standing and seated users.
- Public telephones with convenient shelf space for a TTY (with an electrical outlet close).
- Lowered section of closet rod.
- Door with glass window or sidelight to see others approaching.
- Visible and easily understood directional signage.
- Objects protruding from walls can be detected by canes.
- Refreshment counter with knee space; all items placed within easy reach.
Removing Barriers to Health Care

Additional Features

- Bottom edge of mirror close to countertop
- Trash receptacles must not obstruct clear floor areas at fixtures
- Lavatory with knee space and lever faucet
- Reach to seat cover dispenser must not be obstructed by toilet

Single User Patient Toilet Room

- Loop handle
- Additional counter space for specimen cups and similar items within easy reach
- Full length mirror
- Pass through with ample floor space beneath, loop handle on door
- Shelf height convenient for standing and seated users (36” to 48” recommended)
- Flush or no threshold
- Clear floor space for a 5-foot turning radius
- Non-skid and slip-resistant floor surfaces
- Low, easy-to-reach soap dispenser
- Paper towel dispenser and trash receptacle convenient to lavatory
- Full length mirror
- Focused lighting at lavatory
- Rear and side grab bars extend beside and in front of toilet
- 18” toilet seat height accommodates wide range of users
- Toilet paper within easy reach of user (paper dispenser requires only one hand with continuous paper flow)
- Clear floor space for a 5-foot turning radius
- Flush control on open side of toilet – automatic preferred
- Non-skid and slip-resistant floor surfaces
- Bottom edge of mirror close to countertop
- Trash receptacles must not obstruct clear floor areas at fixtures
- Lavatory with knee space and lever faucet
- Reach to seat cover dispenser must not be obstructed by toilet
Dressing Room

clothes hook 48” max

large dressing bench, at least 24” deep by 48” wide and 17” to 19” above floor

Note: to provide a 32” clear opening, a 36” wide door may have to be installed

Recommended Minimum Sized Toilet Room

at small toilet rooms, door must swing out

full length mirror benefits standing and seated users

clear floor space for a 5-foot turning radius

because room is small an outswinging door must be installed

6’-6”
7’-2”
3’-6”
1’-6”

32” minimum

32”

3'-6”

24”

36”

32” minimum

6’-6”
blood pressure cuff located on side of table with 5-foot turning radius so sufficient clear floor area is available for wheelchair maneuvering

height adjustable and articulating examination table

3 feet minimum clear between table and wall

recommended 5 feet minimum clear to one side of examination table

cabinet with retractable door and roll-out cart provides knee space for a staff member who may use a wheelchair

loop handle hardware

lowered coat hooks

clear floor space for 5-foot turning radius

movable chairs with arm rests

weight scale accommodates people who use wheelchairs

movable chair and clear floor area allows access to blood pressure cuff by people who use wheelchairs or other mobility devices

Examination Area
Creating Accessible Environments and Services

Create a Team of People to Help

Determine and Meet Accessibility Requirements

Creating barrier-free health care environments is an ongoing process that requires input from many people. Designers, builders, and equipment suppliers do not set policies and are not taught to design for or accommodate the full range of human needs and abilities. Building codes and laws cannot correct for this deficiency, so it is important for health care professionals to become active team members in planning for any health care facility or program.

Involving people with a variety of disabilities as part of a team for assessing accessibility and recommending additional accommodations is essential. The lived experience of disability is an excellent resource. Since each person’s experience and knowledge is different, and also because disabilities vary so broadly, seek advice from more than one person. Ask your patients for their input on how to make your facility and services more accessible. Local disability organizations or advocates can provide information on a broad range of disabilities including mobility, cognitive, vision, and hearing and are excellent sources for planning advice.

Provide Customer-based Services

Not all barriers to health care are physical ones. Often, interactions between health care providers and people with disabilities can be awkward and frustrating. Observing some basic rules of disability etiquette will yield greater results and more positive interactions between health care professionals and patients with disabilities.

In General

- Treat all persons with respect. Call a person by his or her first name only when you’re extending this familiarity to everyone present.

- Offer assistance to a person with a disability if you feel like it, but wait until your offer is accepted before you help, and listen to any instructions the person may want to give about the best way to assist them.
When talking with someone who has a disability, speak directly to that person rather than through a companion who may be with them.

Be considerate of the extra time it may take for a person with a disability to get things done or said. Let the person set the pace in walking and talking.

Relax. Don’t be embarrassed if you happen to use accepted, common expressions, such as “See you later” or “Got to be running along” that seem to relate to the person’s disability.

**People with Mobility Disabilities**

- Any aid or equipment a person may use, such as a wheelchair, guide cane, walker, crutch or assistance animal is part of that person’s personal space. Do not touch, push, pull or otherwise physically interact with an individual’s body or equipment unless requested to do so. If it is necessary to move a person’s mobility device, never do so without asking first.

- Always ask before you move a person in a wheelchair, out of courtesy, but also to prevent disturbing the person’s balance.

- If a person transfers from a wheelchair to an examining table, bathtub, toilet, etc., be sure not to move the chair beyond easy reach. If the person uses some other aid, such as crutches or a walker, make sure they remain accessible to the patient.

- Always make sure the wheelchair is locked before helping a person transfer.
- When conversing at length with a person in a wheelchair, sit or place yourself at that person’s eye level, but do not kneel.

- Don’t patronize people who use wheelchairs by patting them on the head.

**People with Vision Disabilities**

- When you offer to assist someone with a vision impairment, allow the person to take your arm. This will help you guide rather than propel or lead them.

- When greeting a person with a severe loss of vision, always identify yourself and others who may be with you. Speak in a normal tone of voice, indicate when you move from one place to another, and let it be known when the conversation is at an end.

**People with Hearing Disabilities**

- To get the attention of a person who has a hearing disability, tap the person on the shoulder or wave your hand.

- Look directly at the person and speak clearly, slowly and expressively to establish if the person can read your lips. Not all persons with hearing impairments can lip read. Those who can rely on facial expressions and other body language to help in understanding.

A roster of certified sign language interpreters should be maintained at each office.
Show consideration by placing yourself facing the light source and keeping your hands and food away from your mouth when speaking. Keep mustaches well-trimmed.

While shouting won’t help, written notes can.

**People with Speech Disabilities**

- Give whole, unhurried attention when you’re talking to a person who has difficulty speaking. Keep your manner encouraging rather than correcting, be patient rather than speak for the person. When necessary, ask short questions that require short answers or a nod or shake of the head.

- Never pretend to understand if you are having difficulty doing so. Repeat what you understand. The person’s reaction will assist you and guide you to understanding.

**People with Cognitive Disabilities**

- Take the time necessary to assure clear understanding. Use simpler words and add gestures while you talk. Use precise language and try to employ words that relate to things you both can see. You may need to write down information or draw a simple picture.

- Be prepared to give the person the same information more than once in different ways.

**Conclusion**

Creating more universally usable health care environments and services benefits all your customers, including those patients with disabilities. Knowledge of existing codes and standards serves as a starting point in meeting accessibility guidelines. Going beyond accessibility requires a partnership with your patients with disabilities. By creating a team, you can meet the intent of the law and foster an atmosphere that welcomes everyone into your health care facility.
Resources

For More Information

Copies of the ADA Standards for Accessible Design (ADASAD) and the Title II and Title III Technical Assistance Manuals are available from the Disability and Business Technical Assistance Center (DBTAC) or the U.S. Department of Justice at:

Disability and Business Technical Assistance Center
(800) 949-4232 V/TTY
Website: wwwadata.org/index-dbtac.html

Public Access Section
Civil Rights Division
U.S. Department of Justice
PO Box 66738
Washington, DC 20035-9998
(800) 514-0301; (800) 514-0383 (TTY)
Website: www.usdoj.gov/

For Design or Product Information, contact:

The Center for Universal Design
College of Design
North Carolina State University
Campus Box 8613
Raleigh, NC 27695-8613
(800) 647-6777 (V/TTY)
(919) 515-3023 (fax)
Website: wwwdesign.ncsu.edu/cud

For a more detailed discussion of the ADA requirements for medical care facilities, you may order the 17 page technical assistance document titled Medical Care Facilities from the Center for Universal Design.

Copies of Removing Barriers to Health Care may be ordered from The Center for Universal Design or the North Carolina Office on Disability and Health. Alternate formats are available upon request. When ordering large quantities, please contact the North Carolina Office on Disability and Health.

The North Carolina Office on Disability and Health
Frank Porter Graham Child Development Center
The University of North Carolina at Chapel Hill
Campus Box 8185
Chapel Hill, NC 27599-8185
(919) 966-2932
(919) 966-0862 (fax)
Website: wwwfpg.unc.edu/~ncodh
Access to Breast Cancer Screening Services for Women With Disabilities
Nancy Mele, Jeanne Archer, and Burton D. Pusch

Objective: To identify barriers to breast cancer screening services encountered by women with physical disabilities.

Design: Phenomenologic design using a semi-structured interview guide to explore the experiences of women with disabilities seeking breast cancer screening services.

Setting: Face-to-face interviews conducted in the homes of women from the urban and rural mid-south.

Patients/Participants: A purposive sample of women with motor or sensory disabilities, age 21 to 65, was recruited for this study based on community type and type and severity of disability. Community collaborators working with people with disabilities identified eligible participants.

Results: Although the study focused on breast cancer screening services, women also described financial, architectural, environmental, and attitudinal barriers that affected all of their health care services. Women described poor transportation, heavy doors, and inaccessible exam tables and bathrooms. They felt devalued by their providers and believed that their symptoms were often overlooked. Women with disabilities want to be partners in their own health care.

Conclusions: Women with physical disabilities face both financial and nonfinancial barriers to access that may result in delayed detection and increased risk of poorer outcomes from breast cancer. Providers require education about working with women with disabilities. JOGNN, 34, 453-464; 2005. DOI: 10.1177/0884217505276158

Keywords: Breast cancer screening—Disability—Health care access—Prevention—Women’s health

Accepted: October 2004

Breast cancer is the second major cause of cancer death in women. This year an estimated 211,240 women in the United States will be diagnosed with breast cancer and 40,410 women will die from the disease (American Cancer Society [ACS], 2005). Unfortunately, the overall picture of breast cancer morbidity and mortality in women with disabilities is unknown because the National Cancer Institute does not collect data on comorbid conditions. Yet women with physical disabilities are equally, if not more, susceptible to breast cancer than women without disabilities (Ross, 1998; Welner, 1999).

The current understanding of the relationship between behavioral factors and cancer risk and the cancer-causing potential of certain environmental factors (ACS, 2005) indicates that women with functional limitations are at increased risk for breast cancer. Women with disabilities are more likely to be exposed to frequent x-rays and prolonged use of medications and to experience differences in exercise, nutrition, and childbearing practices than women without disabilities (Jones, 1999; Ridley, 2000).

Abnormalities that show up on screening mammogram are usually the earliest sign of breast cancer (ACS, 2005). Therefore, regular screening is likely to result in detection of tumors at earlier stages when treatment is more successful. Women with disabilities fit the risk profile for reduced access to health care and therefore are less likely to obtain screening mammograms. They are more likely to be unemployed, live in households with incomes at or below the poverty level, and reside in rural areas, and they are less likely to have postsecondary education (Iez-
The current paradigm of disability strongly emphasizes the role of the environment on life choices and individual goal achievement for people with disabilities (World Health Organization [WHO], 1997). Also, promoting the health of people with disabilities and eliminating health disparities for people with disabilities is a goal of Healthy People 2010 (U.S. Department of Health and Human Services [DHHS], 2000). Therefore, the purpose of this study was to discover the barriers and facilitators that women with disabilities experience when seeking breast cancer screening services, defined as self-breast exam (SBE), clinical breast exam (CBE), and mammogram.

**Background**

Access as a broad concept includes both structural (physical) and functional (sociological) barriers that emerge when a person with special needs attempts to access and use services and facilities available to persons without disabilities (Mace, 1998; Natale & Sprik, 1980). Pierce (1998) found that access to society-at-large invoked feelings of frustration in people who use a wheelchair for full-time mobility. All participants resented being seen as dependent and expressed dismay at the failure of others to make simple adjustments in the environment that would accommodate their needs.

People with disabilities are living longer and, like the nondisabled population, require preventive health services to maintain their health and enhance their overall quality of life (Iezzoni et al., 2001). The primary care provider is the initial point of contact for the health care system and, in many cases, assumes responsibility for coordination of care. Yet many people with disabilities receive only episodic specialty care in place of primary care coordination (Mace, 1998).

Health care facilities are often inaccessible and ill equipped to serve people with disabilities (Grabois, Nosek, & Rossi, 1999; Thierry, 2000). Commonplace procedures like CBEs, Pap smears, and mammograms are overlooked or omitted for women with disabilities because of inaccessible office environments (Mace, 1998; Ross, 1998; Welner, Foley, Nosek, & Holmes, 1999). A qualitative study by Nosek and colleagues (1995) reported that medical system and practitioner characteristics strongly influenced the reproductive health care-seeking behaviors of women with physical disabilities. These women voiced their frustration about architectural barriers and attitudes of practitioners and physicians who did not fully understand the effect of disability on sexuality and reproductive health.

The degree to which women with disabilities participate in screening mammography has been the subject of several studies. A survey of highly educated, moderate income, nonminority urban women found no significant difference in the frequency of mammography between women with disabilities and women without disabilities, regardless of the severity of disability (Nosek & Howland, 1997). However, recent secondary analyses of national databases and supplements have found that significant functional limitation and older age increase the probability of not having recommended screenings (Centers for Disease Control and Prevention, 2004; Chan et al., 1999; Iezzoni et al., 2001; Nosek & Gill, 1998).

Promoting the health needs of women with disabilities has been largely ignored until recently. The literature is largely anecdotal, and the research is limited. Quantitative studies from nationally representative samples have focused on patterns of health-seeking behavior rather than the context within which women with disabilities make health care decisions. To determine that context, this study examines the knowledge, attitudes, and experiences of women with disabilities who should be seeking preventive health services.

**Methods**

**Design, Settings, and Participants**

Using a phenomenologic design, we conducted 20 face-to-face interviews with women, aged 21 to 65, who reside in a predominantly rural, southern state and have either a mobility or sensory disability. Specific types of sensory disability included vision and hearing impairment. Loss of motor function was due to rheumatoid and osteoarthritis, traumatic brain injury, lower limb amputation, stroke, or multiple sclerosis. A purposive sampling strategy using characteristics like disability type and severity, which may have a bearing on the experiences of women with disabilities seeking breast cancer screening services, was used. The sampling plan was designed to maximize the range of features (Table 1). This sampling frame reflects the maximum variation sampling strategy proposed by Patton (2002). The strength of this strategy is embedded in Patton’s logic that common patterns and themes emerging from great variation capture the core experiences of the phenomena under study.

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**Women with disabilities are less likely to obtain recommended breast cancer screening than women without disabilities.**
Interviews were conducted and audio-taped in the participants' homes. All data were collected in the year 2001. The research team was prepared to provide transport services to an alternate location and an attendant for personal care during the interview at the request of the participant. The women were also offered the option of scheduling the interview over two sessions.

**Instruments**

This study used a guided structured interview to ask about the determinants of access to breast cancer screening services for women with physical disabilities. Recommended breast cancer screening services were defined as SBE, CBE, and mammogram. Nosek and colleagues’ (1995) *Heuristic Model of Factors Contributing to Reproductive Health Maintenance Among Women With Disabilities* (Figure 1) was used as a framework for developing questions and probative statements. Although the entire model was used to develop questions, the results from only two concepts of the model, Internal Factors and Environmental Factors, are reported in this article. Precise questions and probative statements from these two concepts are provided in Table 2.

**Procedure**

The sample was selected from the population of women with disabilities served by our community collaborators. Collaborators were given a project overview and letters of invitation for potential participants. Participant letters described the study and asked those who were

<table>
<thead>
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<th>Disability Severity</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>Mixed</td>
<td>6 motor</td>
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<td>21-65</td>
</tr>
<tr>
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<td></td>
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**TABLE 1**

*Sampling Frame*

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**FIGURE 1**

A heuristic model of factors contributing to reproductive health maintenance among women with disabilities.

interested in participating to return a self-addressed, stamped postcard to the research team. The postcard asked for a telephone number and the best time to call for a screening interview. Each community collaborator was given a unique agency code that appeared on the postcard. One collaborator requested a telephone script in place of the letters. Potential participants served by this collaborator received a telephone call instead of a letter. The person making the call described the study using the telephone script and placed the telephone number and best time to call on a postcard that was returned to the research team. A trained recruiter conducted a telephone-screening interview to determine eligibility. The interviewer asked about age, location, type of disability, and severity of disability. Type of disability was classified as motor or sensory. Disability severity was determined using direct or proxy responses to questions about difficulties in performing activities of daily living (ADL). Respondents were categorized into one of three disability groups: mild = 1 to 2 ADL limitations, moderate = 3 to 4 ADL limitations, and severe = 5 to 6 ADL limitations. Women who satisfied the criteria in the sampling frame were invited to schedule an interview in a location of their choice. All women requested a home interview. One member of the research team conducted all interviews. The interviews lasted from 60 to 90 min and were audio-taped using two recording devices. As a type of member checking, the researcher summarized the women’s responses at the end of the interview to verify content. Women were given a $50 honorarium for their participation. A licensed court reporter transcribed the audiotapes for analysis.

### TABLE 2

**Questions and Probative Statements for Internal and Environmental Factors Concepts**

<table>
<thead>
<tr>
<th>Internal Factors</th>
<th>Environmental Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tell me how important it is to perform monthly self-breast exams (SBE).</td>
<td>If you are insured, how well does your insurance accommodate disability-related services?</td>
</tr>
<tr>
<td>How often do you perform SBE?</td>
<td>Additional CBE?</td>
</tr>
<tr>
<td>Tell me how important it is to have an annual clinical breast exam (CBE) and mammogram.</td>
<td>Personal care services for SBE?</td>
</tr>
<tr>
<td>How often do you have a CBE?</td>
<td>Referral to out-of-network specialists with special accommodations?</td>
</tr>
<tr>
<td>When did you have your last mammogram?</td>
<td>Please describe your experiences with the clerical/clinical staff at your provider’s office.</td>
</tr>
<tr>
<td>Tell me about how you manage recommended breast cancer screening services.</td>
<td>Denied appointments?</td>
</tr>
<tr>
<td>Does your regular source of primary care do your CBE?</td>
<td>Attitudes toward making accommodations?</td>
</tr>
<tr>
<td>Does your regular source of primary care ask if you have had a CBE or mammogram in the last year?</td>
<td>Assistance with ADLs or transfers?</td>
</tr>
<tr>
<td>Does your regular source of primary care refer you to another provider for your CBE or mammogram?</td>
<td>Tell me about the last time you had a mammogram.</td>
</tr>
<tr>
<td>Please describe your most positive and most negative experience with the health care system when addressing a preventive health care need.</td>
<td>Making the appointment!</td>
</tr>
<tr>
<td></td>
<td>Having the mammogram?</td>
</tr>
<tr>
<td></td>
<td>Receiving the results?</td>
</tr>
<tr>
<td></td>
<td>Experiences with recall for problems?</td>
</tr>
<tr>
<td></td>
<td>Please describe how you get to and from your provider’s office.</td>
</tr>
<tr>
<td></td>
<td>Type and cost of transportation?</td>
</tr>
<tr>
<td></td>
<td>Eligibility and availability?</td>
</tr>
<tr>
<td></td>
<td>Hours and days of operation?</td>
</tr>
<tr>
<td>Please describe the degree to which your provider’s office is accessible to you and other people with disabilities.</td>
<td>Tell me about the last time you had a mammogram.</td>
</tr>
<tr>
<td>Accessible parking?</td>
<td>Making the appointment!</td>
</tr>
<tr>
<td>Ramps?</td>
<td>Having the mammogram?</td>
</tr>
<tr>
<td>Power-assisted doors?</td>
<td>Receiving the results?</td>
</tr>
<tr>
<td>Accessible bathrooms?</td>
<td>Experiences with recall for problems?</td>
</tr>
<tr>
<td>Elevating exam tables?</td>
<td>Please describe how you get to and from your provider’s office.</td>
</tr>
<tr>
<td>Alternate format for education?</td>
<td>Type and cost of transportation?</td>
</tr>
<tr>
<td>Emergency evacuation?</td>
<td>Eligibility and availability?</td>
</tr>
<tr>
<td>Describe the things that make it easier/more difficult for you to obtain breast cancer screening.</td>
<td>Hours and days of operation?</td>
</tr>
<tr>
<td>Regular reminders?</td>
<td>Accessible parking?</td>
</tr>
<tr>
<td>Disability awareness and accommodation?</td>
<td>Ramp?</td>
</tr>
<tr>
<td>Insurance coverage?</td>
<td>Power-assisted doors?</td>
</tr>
<tr>
<td></td>
<td>Accessible bathrooms?</td>
</tr>
<tr>
<td></td>
<td>Elevating exam tables?</td>
</tr>
<tr>
<td></td>
<td>Alternate format for education?</td>
</tr>
<tr>
<td></td>
<td>Emergency evacuation?</td>
</tr>
</tbody>
</table>
Protection of Human Subjects

Institutional review board approval was granted for this study from the affiliated university. Informed consent was obtained prior to the interview. The consent document was provided in alternate format (Braille, large print, audio-taped, verbal) as needed. Anonymity was maintained in several ways. Only first names were used, and each interview was coded. A master list was maintained by the principal investigator and kept in a locked cabinet. No information that would identify the participant or her location was included in the data set.

Analysis

The data in this study were analyzed using the five phases of the interpretive process described by Miller and Crabtree (1999). During the describing phase, our team conducted a preliminary analysis of eight interviews, reflecting on issues and events that were influencing the interpretation. As a result, adjustments were made in the structured interview guide. The team conducted 12 additional interviews until theoretical saturation was achieved. An editing organizing style was chosen for analysis (Miller & Crabtree, 1999). Each member of the research team individually reviewed the transcripts. The primary analyst identified themes and subthemes through direct interaction with the data by coding, sifting, and sorting the text. Source material was sorted according to type of disability, geographic location, and severity of disability. Connections were made through reflection and engagement with the coded and categorized reports of interview data, field notes, and preliminary analytic memos. Searching for alternative explanations and disconfirming evidence was conducted as a team. Community collaborators and key informants were also invited to provide additional perspectives and suggest alternative interpretive frameworks for analysis during a community forum. Segments of the final report were written as the analysis progressed.

Results

Twenty women completed interviews. Two women in our original sample were unable to participate because of illness that required hospitalization. Others who matched the requirements of the sampling frame replaced them. Selected demographic characteristics of the sample are listed in Table 3. We chose to oversample in group 1 of the Urban Disability Severity cell because our initial recruiting strategies did not yield anyone with a hearing impairment. Recruiting efforts at a school for the deaf identified 3 participants with hearing loss who lived in an urban area and had mild disability severity scores. This article reports results of the analysis for two concepts of the heuristic model: Internal Factors and Environmental Factors. Themes, subthemes, and representative statements for each concept are provided in Tables 4 and 5. Themes and subthemes specific to a type or severity of disability or a geographic location are specified in the narrative. When no categories are reported, the finding applies to women across the entire sample. Although themes and subthemes are not mutually exclusive, for purposes of clarity, each will be discussed individually.

Internal Factors

Beliefs. The first subtheme, “highly valued, rarely done,” reflects that although women with disabilities place a high value on preventive health screenings, they often do not participate in them because of the difficulties associated with living with a disability. Every woman we spoke to believed it was very important to do a monthly SBE and have an annual CBE and mammogram. However, their behavior was influenced by their disability.

Table 3

Selected Demographic Characteristics of Urban and Rural Women (n = 20)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Urban Women (n = 12) (n/%)</th>
<th>Rural Women (8) (n/%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor (n = 12)</td>
<td>7/58 (58%)</td>
<td>5/62.5 (8%)</td>
</tr>
<tr>
<td>Sensory (n = 9)</td>
<td>6/50 (66.67%)</td>
<td>3/37.5 (37.5%)</td>
</tr>
<tr>
<td>Disability severity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group I (n = 7)</td>
<td>6/50 (85.71%)</td>
<td>1/12.5 (12.5%)</td>
</tr>
<tr>
<td>Group II (n = 7)</td>
<td>3/25 (71.4%)</td>
<td>4/50 (80%)</td>
</tr>
<tr>
<td>Group III (n = 6)</td>
<td>3/25 (50%)</td>
<td>3/37.5 (37.5%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>5/42 (62.5%)</td>
<td>1/12.5 (12.5%)</td>
</tr>
<tr>
<td>Single</td>
<td>3/25 (12.5%)</td>
<td>3/37.5 (37.5%)</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>4/33 (30.77%)</td>
<td>4/50 (80%)</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>6/50 (50%)</td>
<td>1/12.5 (12.5%)</td>
</tr>
<tr>
<td>Public</td>
<td>6/50 (50%)</td>
<td>7/87.5 (87.5%)</td>
</tr>
<tr>
<td>Age in years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>31-63 (100%)</td>
<td>39-60 (75%)</td>
</tr>
<tr>
<td>Mean</td>
<td>46</td>
<td>51</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black (n = 2)</td>
<td>0/0 (0%)</td>
<td>2/25 (25%)</td>
</tr>
<tr>
<td>White (n = 18)</td>
<td>12/100 (66.67%)</td>
<td>6/75 (75%)</td>
</tr>
<tr>
<td>Income (in thousands)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20.0</td>
<td>6/50 (50%)</td>
<td>8/100 (80%)</td>
</tr>
<tr>
<td>≥20.0</td>
<td>5/42 (12.5%)</td>
<td>0/0 (0%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1/08 (8%)</td>
<td>0/0 (0%)</td>
</tr>
<tr>
<td>Years of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤12 years</td>
<td>4/33 (30.77%)</td>
<td>5/62.5 (80%)</td>
</tr>
<tr>
<td>13-16 years</td>
<td>8/67 (75%)</td>
<td>3/37.5 (37.5%)</td>
</tr>
<tr>
<td>&gt;16 years</td>
<td>0/0 (0%)</td>
<td>0/0 (0%)</td>
</tr>
</tbody>
</table>
Women spoke of spasms, pain, immobility, and lack of strength as reasons for not performing SBEs, and some were too embarrassed to ask for help from a spouse or personal care attendant. The overwhelming nature of living with a disability can also result in forgetting to take care of preventive health needs. However, when there was a sentinel event like a lump, a biopsy, or a family member with breast cancer, screening behaviors improved dramatically (prejudiced by own and others’ experiences). One woman who was too young to begin recommended screening mammography asked her primary provider to refer her for a mammogram after a relative was diagnosed with breast cancer. Others began regular SBE following the discovery of a lump or having a biopsy.

Knowledge. Knowing how to perform screening was another barrier. Women told us they lacked the confidence to perform an SBE because they did not know how to do it or what to look for (knowledge breeds confidence). Those with sensory impairments stated that educational materials were not in an alternate format that was accessible to them (subject to external factors). One woman with a hearing impairment shared her experience with her first mammogram where she was shown a video about performing SBE that was not close-captioned. Unable to benefit from the video, she turned off the VCR and waited for her mammogram.

Alternate format was not the only external factor that affected knowledge. Women told us that their primary
TABLE 5
Environmental Factors: Themes and Representative Statements

<table>
<thead>
<tr>
<th>Themes</th>
<th>Functional Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structural Barriers</strong></td>
<td><strong>Interacting With the System</strong></td>
</tr>
<tr>
<td>Restricting Physical Access</td>
<td>Knowledge, attitudes, and behavior</td>
</tr>
<tr>
<td>Gaining access</td>
<td>Nonprofessional staff</td>
</tr>
<tr>
<td>Health insurance</td>
<td>Professional staff</td>
</tr>
<tr>
<td>Transportation</td>
<td>Providers</td>
</tr>
<tr>
<td>Accessible parking</td>
<td></td>
</tr>
<tr>
<td>Gaining entry</td>
<td>Etiquette</td>
</tr>
<tr>
<td>Doors</td>
<td>Routines</td>
</tr>
<tr>
<td>Bathrooms</td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Courtesy</td>
</tr>
<tr>
<td>Equivalent Care/Universal Design</td>
<td>Partnership</td>
</tr>
<tr>
<td>Exam tables</td>
<td>Responsibility</td>
</tr>
<tr>
<td>Alternate format</td>
<td>Respect</td>
</tr>
</tbody>
</table>

**Representative Statements**

“A lot of gynecologists do not accept Medicare patients... That’s a real barrier for a lot of women, because I’m on disability. That’s why I’m on Medicare, even though I’m not 65.”

“I have to have Medicaid transportation to carry me to and from... you may have to sit and wait for hours for them to transport you back home... Lot of long waits. A lot of unnecessary stuff that goes on. You have to call two or three days ahead of time and sometimes... you haven’t got time to give them that kind of notification.”

“Most of us with disabilities have chronic health problems... If we don’t go anywhere else, we go to a doctor. And I have not always found doctors’ offices to be particularly accessible... and that’s just incredible to me.”

“You’d be surprised that when you get to a certain stage with a disability, how hard it is to open a door. You can’t. You know, you eventually get it open, but you have to really work at it, you have to really jerk on that door to get that door open.”

“Sometimes in my regular doctor’s office he’ll just listen to my chest while I sit in a chair instead of getting up on the table.”

“Nurses are supposed to know how to handle disabled people but they don’t. Nurses don’t. They don’t know how to guide you. Every nurse that I have ever encountered... in the last 10 years, I have always had to tell them, ‘Let me take your elbow.’ They grab me by the shoulder or by the arm or by anywhere.”

“When you’ve got one hand, people don’t understand that you’ve got this phone in this hand, and... to get a hold of my doctor, you’ve got to punch one, punch three, punch four, and that makes me mad. I can’t do that and hold the phone... like I run out of medicine and I tried to get a hold of [my doctor]... It took me 3 days... because of his phone system over there.”

“I like to be recognized that I am there... say my husband’s in there... they talk over me like... I’m invisible.”

“I’ve been nice to these medical professionals as long as I’m going to be. They just call your name from across the room. They don’t look at the chart to see if anybody’s handicapped or not... they just walk to the door and yell across the room. So I did something I’d never done before. I stood up and yelled back ‘I am blind and you need to come get me and you ought to know that by now.’ I’ve never done that in a doctor’s office before and I thought there’s a first time for everything.”

“I know that I have a responsibility on my part to ask questions or clarify something that I do not hear. But they need to meet us half way.”

“I tell them I have a hearing loss... What you have to understand about me is I’m an educator... I’m going to tell them, ‘Hey here’s the deal. You’ve got to learn about this.’ But I’ve had some experiences where they were put off by it, it didn’t matter to them.”

Care providers were not teaching SBE or ensuring a reliable source of information by asking if they had a regular source of gynecological care.

**Medical Experiences.** Previous negative health care encounters had a profound effect on the way these women viewed their place in the health care system.
Women could not count on the medical profession to advocate for them, so they felt forced to be their own advocates (affects health-seeking behavior). For the most part, they were willing to fight for what they needed, but they resented being regarded as “that person with a disability . . . that all she does is gripe about the way things are.”

Women also reported experiences in which their nondisability-related health care needs were ignored and they felt dehumanized, degraded, or insulted (altered perception of self: devalued). One woman was repeatedly told that she had “fallen through the cracks.” She interpreted this remark to mean that her life had no significance, which she attributed to her disability.

At worst, providers failed to thoroughly investigate reported symptoms, and critical conditions were overlooked (threatens overall well-being). One woman described an encounter with her rheumatologist where her complaints were dismissed. Her condition ultimately resulted in a prolonged hospitalization for pancreatitis. Another woman’s symptoms were disregarded, “like I was just inventing a problem,” until she was hospitalized with encephalitis.

Environmental Factors

The model lists six environmental factors that influence internal factors and affect reproductive health maintenance. In this study, these environmental factors were organized according to structural and functional barriers. Structural barriers are those that restrict physical access. Functional barriers are more subjective and occur when the woman with a disability interacts with the health care system.

Structural Barriers. Health insurance, transportation, and accessible parking were the most common barriers in the “gaining access” subtheme. Insurance policies and reimbursement practices influenced participation in gynecologic care and mammography. Women with direct access were more likely to see a gynecologist than those who required a referral from a primary provider. Referrals for mammography came primarily from gynecologists. However, having a third party payor for preventive health services was not enough to alter some participants’ behaviors. Some women avoided their well-woman visits for fear that the doctor would prescribe a medication they could not afford. Others who had limits on the number of covered visits saved those visits for when they were ill, and not for preventive services.

Participants living in rural and urban areas reported similar problems in gaining access to transportation. They spoke of cumbersome application processes; income eligibility criteria that were too low for families where one spouse worked; 2- or 3-day advanced notification for service; limited hours of operation; limited coverage areas; and long wait times, especially for the trip home. Women told us that if they were not at the curb within 10 minutes of their scheduled pickup, they would have to call and reschedule their return trip, often delaying their return by several hours.

Despite important advances made by the Americans With Disabilities Act (ADA, 2004), access to providers’ offices remained difficult for most of the women interviewed. They identified accessible parking as unavailable, unenforced, and too far away. Several women used power wheelchairs in their homes but did not have vehicles to transport them. Therefore, they used manual chairs when they were out but did not have the upper body strength or stamina to push their manual chairs the long distances to and from the parking lot.

The “gaining entry” subtheme reflects the problem women with disabilities face with doors and bathrooms. Women complained that doors were heavy, revolving, or locked, and it was a rare occasion that someone was there to help open them. Generally speaking, the bathrooms in their providers’ offices were not accessible. When they were, the doors did not lock automatically, increasing anxiety about privacy in those without the manual dexterity to lock the door. Toilets were also too close to the wall, making transfer difficult or unsafe.

The “equivalent care/universal design” subtheme reflects the absence of supports and assistive equipment for people with disabilities that make obtaining regular health care services possible. Women with mobility impairments were asked if their providers had an accessible style exam table that would facilitate transfer from a wheelchair. Not one could recall ever seeing or using one. Rather, they spoke of high tables with narrow steps for mounting that could tip under their weight. Those who had partial mobility would stand and support their weight on the table until they could mount it with assistance. Others remained in the wheelchair for a partial exam. Platform scales were not available. If the women were weighed, it was done on the regular office scale with assistance as needed.

Functional Barriers. The model lists knowledge and attitudes of medical professionals as two separate external factors. In our study, we found it difficult to separate the two. Also, the model makes no allowance for provider behavior. We believe these three attributes to be inextricably linked. Therefore, our first functional barrier subtheme is “knowledge, attitude, and behavior of health care personnel.” Our definition includes everyone that a woman with a disability is likely to encounter in an office setting, including office staff, nursing staff, and medical providers. For the most part, the women said the office staff, professional staff, and providers were nice to them and made efforts to accommodate their special needs. However, the women’s stories revealed a knowledge
Discussion

Women with disabilities require access to preventive health services to improve the quality of their reproductive health care. Yet internal and external factors act as barriers that may result in delayed detection and increased risk of poorer outcomes from breast cancer.

Women with disabilities face barriers to access that may result in delayed detection and increased risk of poorer outcomes from breast cancer.

Although women with disabilities place high value on breast cancer-screening activities, many do not perform SBE because of the effects of the disability or because they do not know what to do or what to look for. Educational materials that are not available in alternate format contribute significantly to this knowledge deficit. Women also reported that their primary care providers were not teaching SBE, doing CBE, referring for mammograms, or making sure that they had a regular source of gynecologic care for these screenings. This would appear to support the contention that people with disabilities receive poorer quality health care than women without disabilities (Mace, 1998; Ross, 1998; Welner et al., 1999).

Despite substantial legal requirements for providing environmental access, women still face problems with transportation, accessible parking, and gaining entry to providers’ offices. Most women relied on family and friends for transportation for a variety of reasons: (a) the advanced notification requirements and long wait times associated with public transportation, (b) absent or unavailable accessible parking, and (c) having to have help with heavy or revolving doors to access their provider’s building. More rural women reported using public transportation than did urban women, but cumbersome rules and regulations were the same regardless of the geographic area. Women who had their own transportation worried about finding accessible parking because of the misuse of accessible parking tags and poor law enforcement regarding accessible parking.

The potential loss of their source of private transportation, like a spouse who could no longer drive, was also a concern. Doors without power assist provided a structural barrier that could only be overcome with assistance from others. Similar to the findings of Pierce (1998), the women in this study resented being seen as dependent and were frustrated at a system that failed to make adjustments to support their needs.

Previous experiences with the health care system have a profound effect on the attitudes and health-seeking behaviors of women with disabilities. These women have
learned that they must be their own advocates because the health care system will not look out for their best interests. Providers have little knowledge of disability etiquette or supports needed to make routine health care possible for this population. For example, providers’ offices lack adjustable examination tables and platform scales, which may result in commonplace procedures or parts of the physical exam being omitted. Personnel make little effort to alter the environment or office routines to accommodate the needs of women with disabilities, like providing extra time for the visit or asking the women how they want to be helped. Accommodation is often viewed as an inconvenience in the staff’s busy schedule, and women with disabilities are labeled as complainers. Their nondisability-related health care needs are overlooked, and they are often disrespected and devalued in their encounters with their providers.

Women with disabilities want to be full partners in their health care. They don’t expect their providers to know everything about their needs as a person with a disability. But they do expect providers to accept information without being defensive.

The concepts of the heuristic model proposed by Nosek and colleagues (1995) and tested by this study were substantiated. Internal and environmental factors were found to contribute to a lower quality of reproductive health maintenance among women with disabilities. However, elements of the model need to be refined. Environmental factors were found to be more discriminating if viewed as either structural or functional. This study also found that knowledge and attitudes of medical professionals could not be separated from their behaviors. And it was provider behavior that had the greatest impact on the women’s knowledge, beliefs, and medical experiences.

Although qualitative data are not generalizable in a statistical sense, rich description of the context within which women with disabilities make health care decisions provides insight into the barriers and facilitators these women experience when seeking breast cancer screening services. Ultimately, this insight may contribute to full participation in life-saving health services for this population as well as contribute to the elimination of disparities in access to health care between people with and without disabilities.

**Limitations and Future Research**

A major limitation of this study is the omission of women with mobility impairments who use a wheelchair for full mobility. It was anticipated that including those with severe limitations in the performance of ADLs would capture this population. However, all of the women who participated in this study were able to stand for short periods of time with assistance. Information about the health care encounter and the experience of having a mammogram for a woman with no lower extremity motor function may yield different barriers to reproductive health management and provide further clinical implications for this population. Women with developmental and psychiatric disabilities were also excluded. This study also found that women had difficulty separating their acute care experiences from preventive health visits. This may have altered the responses to questions about access and accommodation. Additional studies are needed that focus only on the mammogram encounter. Using research methods that use direct observation rather than recall of lived experiences is likely to yield richer and more reliable data.

**Implications and Conclusions**

The degree to which women with disabilities participate in breast cancer screening will largely be determined by structural access to health care facilities. The Americans With Disabilities Act of 1990 (ADA) makes it illegal to discriminate against individuals with disabilities. Title III of the ADA requires the removal of all structural barriers in existing facilities that are easily accomplished without great difficulty or expense. All new construction or alterations requiring a building permit must comply with the ADA guidelines for accessible design before opening (Grist et al., 1996). An appropriate time for nurses and other health care providers to consider components of accessible design like the height of countertops, the layout of exam rooms, and the purchase of universally accessible equipment is during new construction or renovation.

Positive interactions between women with disabilities and their providers also increase the likelihood that those women with motor or sensory impairments will seek reproductive health services. Nurses can make encounters with the reproductive health care system for women with disabilities rewarding and satisfying by implementing appropriate nursing interventions that are informed by the elements of disability etiquette—sensitive communication, courtesy, and accommodation. Becoming familiar with the ADA and using a team approach to meet accessibility and accommodation requirements is critical.
Providers should involve people with disabilities, seek advice from disability organizations, and ask patients with disabilities for their input about ways to best meet their needs. Remember that assistive technology and adaptive techniques create a bridge between how the body works and the environment. Nurses should view these devices and techniques as promoting health rather than denoting illness. Accommodation requires that you consider the assistive device as part of the woman’s personal space and make sure that mobility aids remain accessible to the woman with a disability at all times, even if she is on an examination table. The nurse conveys respect for a person with a disability by not touching or moving the device until asked or given permission to do so.

When addressing a woman with a mobility disability, make sure you speak directly to her. Establish level eye contact by sitting if necessary, and do not direct questions to those who accompany her. A woman with a hearing impairment may require an interpreter or read lips. When communicating with her, the nurse should speak clearly and slowly so she may use your facial expression and body language to aid understanding. A woman with a visual impairment can be intimidated when unknown people enter the examination room without identifying themselves. She will be much more comfortable if you introduce yourself and others that are with you, especially if you indicate when you plan to move from one place to another. Regarding the woman’s face, speaking in a normal tone of voice and acknowledging the end of the conversation during the encounter communicates that you are comfortable with her and her disability.

Courteous behavior requires that you offer her your arm as you guide rather than lead her to and from the examination room. A therapeutic interaction is more likely to occur when you ask for, and listen to, instructions from a woman with a disability about how best to help her. When offering assistance, wait until your offer is accepted before you help. Women with disabilities want to be partners in their own health care, so let the woman with a disability set the pace of the visit and allow extra time for the appointment. Using disability etiquette communicates that you respect and value the woman with a disability. When she is treated like someone who has the same concerns about health and health care as any woman, she is likely to fully participate in life-saving health services like SBE, CBE, and mammography. Full participation increases the chances for early detection, increased treatment options, and better outcomes.

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REFERENCES


July/August 2005


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Going beyond Disease to Address Disability
Lisa I. Iezzoni, M.D.

One summer day about 10 years ago, a young woman flagged me down as I was rolling back to my hospital on my scooter wheelchair. An inpatient taking a sunshine break, she sat on a bench, intravenous pole in tow. She explained, tears brimming, that complications from diabetes made walking increasingly difficult. She was a single mother, and she could no longer get to the grocery store. She had asked her physician to prescribe a power wheelchair, but he had refused, insisting that she keep walking. Unable to meet her family’s basic needs, she had bought a cheap manual wheelchair, and her 10-year-old son, barely tall enough to see over her, pushed her to the store. “How can I get a scooter like yours?” she asked.

This story, among the first told by my “rolling focus group” — strangers who ask me about living with disability — started me thinking. Although the tales are as diverse as the tellers, they have two common themes: a desire to remain active and independent, and a quest for information about options that permit educated choices for conducting daily activities and maximizing the quality of life. A lack of open, productive, informative dialogue with physicians can impede, delay, or derail these choices. This woman’s doctor had a legitimate concern regarding physical activity, but she still needed groceries. Together, they might have devised solutions to meet both her health and practical needs; instead, she felt anxious and abandoned. What is the physician’s role in going beyond treating disease to address dis-

**Selected Medical School Activities Related to Patients with Disabilities**

**Tufts University School of Medicine, Boston**

*Standardized Patient Educator Curriculum, Family Medicine Clerkship.* In this required third- or fourth-year clerkship, persons with disabilities serve as standardized patients in simulated medical interviews, integrating a common primary care concern with disability-related issues; they then provide narrative feedback to students about their behavior, attitudes, and skills in the interview.

**University of Medicine and Dentistry of New Jersey, New Jersey Medical School, Newark**

*Standardized Patient Exercise, Pediatric Clerkship.* During their pediatric rotation, all third-year students spend one day at Matheny Medical and Education Center, which serves children and adults with developmental disabilities. After introductory sessions, each student performs a 20-minute interview with a standardized patient, an adult who is nonverbal because of cerebral palsy and has been trained to represent common medical conditions. After the interviews, standardized patients provide feedback using electronic communication devices or yes-or-no responses to questions.

**University of South Florida College of Medicine, Tampa**

*Caring for Adults with Disabilities.* This module is integrated into the 16-week primary-care clerkship for third-year students. It addresses older adolescents and adults with physical, sensory, and cognitive disabilities through two afternoon seminars with guests from the local community of persons with disabilities; home and community visits; service learning projects; and writing a reflection on the experience.

**University of Illinois–Chicago College of Medicine, Chicago**

*Annual Disability Plenary Session.* This half-day session is part of a required Essentials of Clinical Medicine course for second-year students. Presentations vary from year to year, including performances by artists with disabilities, films about living with disability, and presentations from faculty members with expertise in caring for persons with specific disabilities.

**University of Pennsylvania School of Medicine, Philadelphia**

*The “Wheelchair Experience.”* This four-hour disability simulation is required of all first-year students as part of the Doctoring I Professionalism and Humanism curriculum. Students work in pairs, one using a wheelchair to perform specified day-to-day tasks while the other serves as caregiver; students then switch roles. Afterward, students write a two-page essay about the experience. In addition, a person with a disability or a family caregiver interacts with students in small groups, describing disability-related experiences and answering students’ questions.

**University of Massachusetts Medical School, Worcester**

*Community Health Clerkship in Disability and Long-Term Care Policy.* This clerkship offers an elective, two-week curriculum for first-year students, in partnership with a community organization. It teaches students about living with a disability, community resources, and how physicians can enhance the ability of persons with disabilities to lead full lives in the community.
ability? And how should doctors be taught to fulfill this role?

Although physicians learn volumes about treating underlying causes, many receive little training in addressing resultant disability — difficulty performing daily activities and fulfilling social roles because of physical, sensory, emotional, or cognitive impairment, often compounded by environmental barriers. Approximately 54 million Americans currently live with some type of disability. Medical interventions now allow many persons with clinically significant congenital conditions or impairments acquired in childhood or early adulthood to live long, productive lives. With baby boomers moving into their seventh decade, the number of persons with disabling conditions, such as impaired walking, hearing, vision, speech, or cognition, will soon skyrocket. Given the rising rates of childhood obesity, asthma, diabetes, and arthritis, disabilities may develop at younger ages. Virtually all active clinicians can expect to see persons with disabilities in their practices.

Despite these demographics, efforts to train physicians to address disability confront substantial challenges. Chronic disability can thwart physicians’ motivation to cure diseases. Some physicians see disability as outside their purview: “It’s social-worker–type stuff,” a general internist told me. Our society has historically marginalized persons with disabilities, and many physicians have internalized common views. “My upbringing was like everybody else’s,” another general internist observed. “Don’t talk about it, don’t stare, it’s somehow hurtful.” Patients may perceive this discomfort or wonder what their doctors can do anyway. Disability becomes the elephant in the room — present, but unmentioned.

Such attitudes carry consequences. In 2000, the Healthy People 2010 initiative identified Americans with disabilities as vulnerable to substandard care, asserting that erroneous assumptions about this population contribute to disparities in services. In a “Call to Action” issued July 26, 2005, the 15th anniversary of the Americans with Disabilities Act (ADA), the U.S. Surgeon General urged health care providers to treat persons with disabilities with dignity, as whole persons.

One place to begin physicians’ training about disability is the realm of patient–physician communication. Communication is key to achieving patient-centered care, a touchstone for improving the quality of health care. Care that respects patients’ preferences, needs, and values has special resonance for persons with disabilities, who often find others defining and circumscribing their health care experiences, needs, and preferences of women with disabilities (kkirschner@ric.org).
PERSPECTIVE

lives and options. A patient-centered orientation requires open communication between patients and physicians, unhampered by false assumptions about patients’ abilities and aspirations. Optimal care then demands collaboration between patients and physicians, each bringing their respective expertise to decision making: physicians possess critical technical knowledge, but patients are the experts on their own lives.

Communication between physicians and persons with disabilities can falter on many levels. An initial barrier arises when physicians “medicalize” disability. Although diseases do produce disability, persons with long-term disabilities do not necessarily approach their conditions as illnesses. “I’m not sick,” says a woman who has had multiple sclerosis for 30 years. “I just can’t stand up!” Rather than seeking treatment for her disease, she wants advice about performing daily activities, perhaps with assistance, at home. “The medical community has a pathologic view of deaf people,” said a deaf woman who communicates using sign language. “They don’t see us as a linguistic minority. I don’t identify myself as disabled.” When she visited the emergency room with an injured ankle, the physician’s first question was about why she was deaf.

The ADA and other laws require clinicians to communicate effectively with patients, but physicians don’t always do so. For instance, they often write notes to deaf patients, not recognizing that some sign-language users may have low proficiency in English. Hospital policies required a woman to relinquish her hearing aids before surgery. “Afterward, they told me, ‘You took a long time to come out of anesthesia. We kept talking to you.’ But I couldn’t hear them!” An elderly man, hospitalized because of deep-vein thrombosis, was given written instructions along with injectable medications to self-administer at home. The nurse and pharmacist who counseled him on discharge failed to recognize that he was blind. Unable to read the instructions, he didn’t take his medication.

Uninformed assumptions about persons with disabilities can erode respect and trust, the bedrock of open communication. For instance, physicians may underestimate the intelligence of persons with communication disorders, such as speech impairments related to cerebral palsy (see shaded box). “When doctors hear I have a psychiatric disability, they question my judgment on everything,” said one woman. “I don’t have a relationship of trust.” Persons with disabilities sometimes fear that physicians may not treat acute conditions aggressively, believing that the patient’s quality of life is poor anyway.

Some persons with disabilities note that their physicians do not make basic connections between functional impairments and daily needs. “When my shoulders were hurting, my doctor told me, ‘Don’t use your arms so much,’ ” reported a woman who self-propels her wheelchair. “I’m paraplegic — all I have is my arms! How can I get around without them?” Physicians may not acknowledge that people with long-term disabilities often know more about their conditions than their doctors do. Several persons with spinal cord injury reported physicians’ refusal to believe that they could feel pain below the level of their injuries. One physician biopsied a leg lesion without administering local anesthetic.

Finally, many persons with disabilities believe that physicians do not appreciate the richness of their lives, leaving them feeling disrespected or degraded. Some offenses, such as speaking to sign language interpreters rather than directly to deaf patients or grabbing the arms of blind persons when escorting them to examining rooms, probably reflect poor training. Others represent basic failures of physicians to imagine full and varied lives for persons with disabilities. “Come see us in our own environment,” urged one

“One summer during college, I worked at a rehab engineering center, where we gave assistive technology to people who needed it, mostly communications technology.

“This woman in her 20s came in. She was in a wheelchair and couldn’t speak. Her head was to one side, and she was drooling. We all spoke to her as if she were a little child. She wasn’t responding, and I thought she didn’t understand a word I said.

“We set her up with a computer with word-prediction software with various shortcuts. . . . We were trying to teach her how to use it, telling her to hit the F button. She kept missing the F button and hitting the bathroom button, and we’d say, ‘That’s okay. You’re doing great!’ Finally, someone had the good sense to say, ‘Do you need to go to the bathroom?’

“Then we got her set up with the word-processing program. Within about two seconds, she typed, ‘This is just like having a baby. You wait nine months and then go to the hospital.’ The baby was her getting the computer after waiting for so long. This was not at all what I had imagined from looking at her! I remind myself about this again and again — not to make assumptions based on how disabilities look.”

— Fourth-year medical student
wheelchair user. “Doctors anticipate a much lower quality of life than we actually have.”

Unfortunately, structural barriers within the health care system can impede complete communication and efforts to provide patient-centered care to persons with disabilities. Health insurance does not reimburse more for patients who require extra time or resources (e.g., to make communication or physical accommodations, to consider complex health care needs, or to complete disability-related paperwork). In many circumstances, physicians must enlist colleagues from other disciplines, such as rehabilitation professionals and technology experts, to address patients’ concerns fully — requiring even more time to communicate and coordinate care. In addition, health insurance may not cover the long-term rehabilitation and assistive technology that patients need.

Even without extra time, training, and resources, however, two basic precepts can help to build better communication between physicians and persons with disabilities — and perhaps better care. First, make no assumptions. Second, just ask persons with disabilities — about their needs, preferences, and lives.

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BECOMING A PHYSICIAN

The Script

Benjamin Brody, B.A.

“What happened?” the patient asked. She was coming out of anesthesia after six hours of surgery. A weary resident cleaned dried blood and iodine from the skin around the surgical wound on her abdomen. The anesthesiologist had just removed her breathing tube. The patient, to my surprise, was staring straight at me — the medical student. She asked again: “What happened?”

During the previous 6 months, a rapidly expanding abdominal mass had developed. Early in her surgery, a frozen section had been sent to the laboratory, and 20 minutes later a voice over the intercom had confirmed what the surgeons had surmised: she had ovarian cancer. The tumor had spread through the pelvis and abdomen, attacking the uterus and loops of bowel. The surgeon and residents meticulously resected all visible disease, but the prognosis was grim and everyone in the operating room knew it — except the patient. But surely it was not my place to relay this news.

The surgeon bailed me out. “Your surgery’s over,” he said in a calm, soothing voice. He told her they would talk more when she had fully awakened. But what — and how, exactly — would he tell her?

In medical school, we’re taught to follow a script: “What brought you to the hospital today?” it begins. It’s a starting point based on the assumption that you haven’t already read a triage nurse’s notes, reviewed the results of laboratory tests ordered in the emergency department, or met the patient during a previous examination. We learn to take a detailed history of the present illness before proceeding to the medical history, the social history, and a series of questions: Current medications? Allergies? Surgical history? Prior hospitalizations? “Ask the questions in the same order, and you’ll never forget anything,” I was advised during my medicine clerkship.

“But I’ve already answered these questions five times,” patients occasionally protest midway through the script. “I’m sorry, but it’s important that we don’t miss anything,” I respond, noting that the patient is alert and oriented. From the first weeks of medical school through the licensing exam, this initial encounter is the focus of medical education. Whether you’re examining an elderly woman with diabetes who has a foot ulcer, a young man having a panic attack, or a vomiting infant, instructors drill this script into your head. Taking his-