



American Association on Health and Disability (AAHD)

ASTHO Learning Community Webinar

Roberta Carlin, MS, JD

Barbara L. Kornblau, JD, OTR



American Association on Health and Disability

- AAHD Mission: To promote health and wellness for people with disabilities
 - Reduce Health Disparities
 - Advocate for Community Inclusion
 - Promote Full Accessibility
 - Integrate Disability into Public Health Agenda



Webinar Overview

- AAHD Overview
- AAHD and Susan Komen Funded Projects (2007-2018)
- Resources and Materials Overview
- Data, Health Disparities and Double Burden
- Survey Results – Major Challenges
- Lessons Learned/Best Practices/What Can You Do In Your Community



Health Disparities

- According to HHS, 12.5% of population has a disability which “seriously limit” them
- People with a disability are:
 - Over twice as likely to not see a doctor due to cost
 - Over 30% more obese
 - 60% more likely to smoke
 - Over 2.5 times more likely to develop diabetes



Health Disparities and Women with Disabilities

- Women with a disability are:
 - Less likely to have a current mammogram
 - Less likely to have a current pap test



AAHD and Susan G. Komen

- 6 Community and National Grants
 - 2007 - 2019



Mammography Facts

- Almost 18% of female population (16-64) live with a sensory, physical or emotional disability
- Women with disabilities, especially those with significant limitations, receive mammograms less often and are diagnosed at a later stage
- Disparity stems from a combination of environmental, attitudinal, physical and communication barriers.



AAHD & Breast Cancer for Women with Disabilities - Overview

- 2007 - “Increasing Screening for Women with Disabilities in Montgomery County, MD By Improving Access, Education and Training at Mammography Sites” (Montgomery County, MD)
- 2009- 2010 – “Project Accessibility Removing Barriers for Women with Disabilities” (MD,VA)



AAHD & Breast Cancer for Women with Disabilities - Overview cont'd

- 2011 -2012 – “Bridging the Gap: No Woman Left Behind” (Washington, DC Wards 7 & 8; Prince George’s County, MD; Arlington County, VA; Prince William County, VA)
- 2012 – 2014 – “Project Accessibility USA: Removing Barriers for Women with Disabilities”
- 2016 – 2018 – “Breast Cancer Awareness for Women with Disabilities: Lightning Can Strike Twice” (Washington DC, Wards 2,5,7, & 8)



AAHD & Breast Cancer for Women with Disabilities – Overview cont'd

- 2018 -2019 – “Breast Cancer Awareness for Women with Disabilities – Lightning Can Strike Twice” (Washington, DC – Wards 2, 5, 7, & 8)



AAHD & Breast Health for Women with Disabilities

- www.aahd.us - AAHD website
- <https://www.aahd.us/initiatives/susan-g-komen-grants>

Fact Sheets, Posters, Tip Cards, Mammography Facility Assessment, Client Reminders



Lightening Doesn't Strike Twice, Right?



Women with disabilities are as likely to get breast cancer as the general population, and some women with disabilities have more factors for getting breast cancer than women in general.



Susan G. Komen Funded Project: 2016-2018

- Identified Wards 2, 5, 7, & 8 high rate of breast cancer in DC
- Complete Facility Assessments of FDA Mammography Facilities
- Community Workshops for Women with Disabilities
- Educational Workshops for Community Organizations
- Partnering with Association of Public Health Nurses, UNM School of Medicine, national disability organizations, area hospitals, Komen grantees and District and community-based organizations



Who Gets Breast Cancer?

- Breast cancer is the most common cancer among African-American women.
- Overall, breast cancer incidence among African-American women is lower than among white women. However, for women younger than 45, incidence is higher among African-American women than white women.



African-American Women and Breast Cancer

- African-American women tend to be diagnosed at a younger age than white women.
- Breast cancer is the second leading cause of cancer death among African-American women (lung cancer is the major cause of cancer death).

Howlader N, Noone AM, Krapcho M, et al. (editors). SEER Cancer Statistics Review, 1975-2013. Table 1.12. National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2013/, 2016; American Cancer Society. Cancer Facts and Figures for African Americans 2016-2018. Atlanta, GA: American Cancer Society, 2016.



African-American Women and Breast Cancer

- Triple negative breast cancers are more common among African-American women than among women of other ethnicities.
- Triple negative tumors are more difficult to treat and have a poorer prognosis compared to other subtypes of breast cancer (at least within the first 5 years after diagnosis).

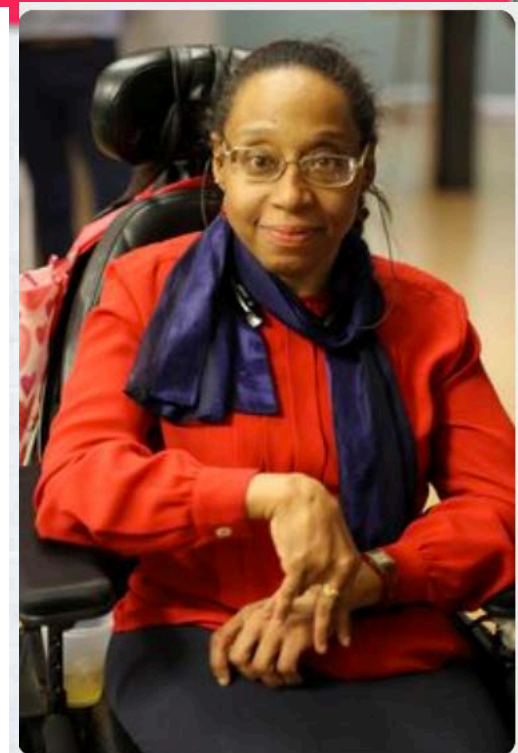


African-American Women and Breast Cancer

- Breast cancer screening rates among African-American women are similar to those among white women.
- Breast cancer mortality is nearly 40 percent higher in African-American women than in white women.
- Although breast cancer survival in African-American women has increased over time, survival rates remain lower than among white women, a significant health disparity



When You Add Disability to REM Status





The Double Burden

- “Aside from the public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic barriers, and difficulties accessing care as a result of their disability—in effect, they face a “double burden.”

HHS Advisory Committee on Minority Health, *Assuring Health Equity for Minority Persons with Disabilities: A Statement of Principles and Recommendations*. (July 2011) at 11.



Amplifying Phenomenon

- “Individuals from minority racial/ethnic groups who also have disabilities confront an enormous health disparity amplifying phenomenon.”

Drum C, McClain MR, Horner-Johnson W, Taitano G. (2011). Health disparities chart book on disability and racial and ethnic status in the United States. Institute on Disability, University of New Hampshire.
http://www.iod.unh.edu/pdf/Health%20Disparities%20Chart%20Book_080411.pdf.



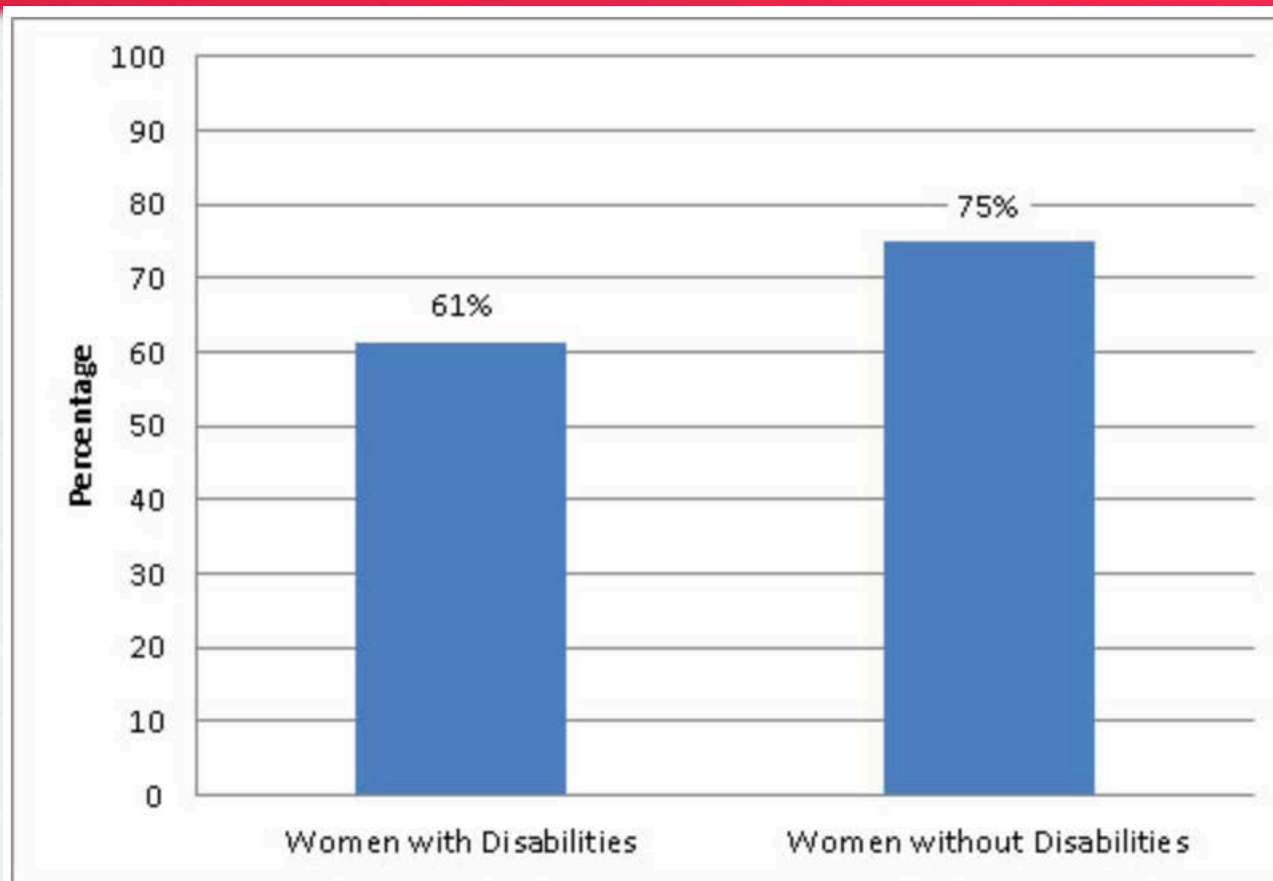
Disability-Based Health Disparities

- According to Healthy People.gov (2014) women with disabilities are less likely to have had a mammogram in the past two years, compared to women without disabilities.
- Multiple reasons for these disparities have been identified in the literature, such as
 - lack of knowledge among women with disabilities about the importance of getting regular mammograms (Li-Wei-Wu, 2012)
 - underutilization of mammography among people with disabilities related to finances, environment, lack of physician referral and lack of awareness (Courtney . Long, 2011).



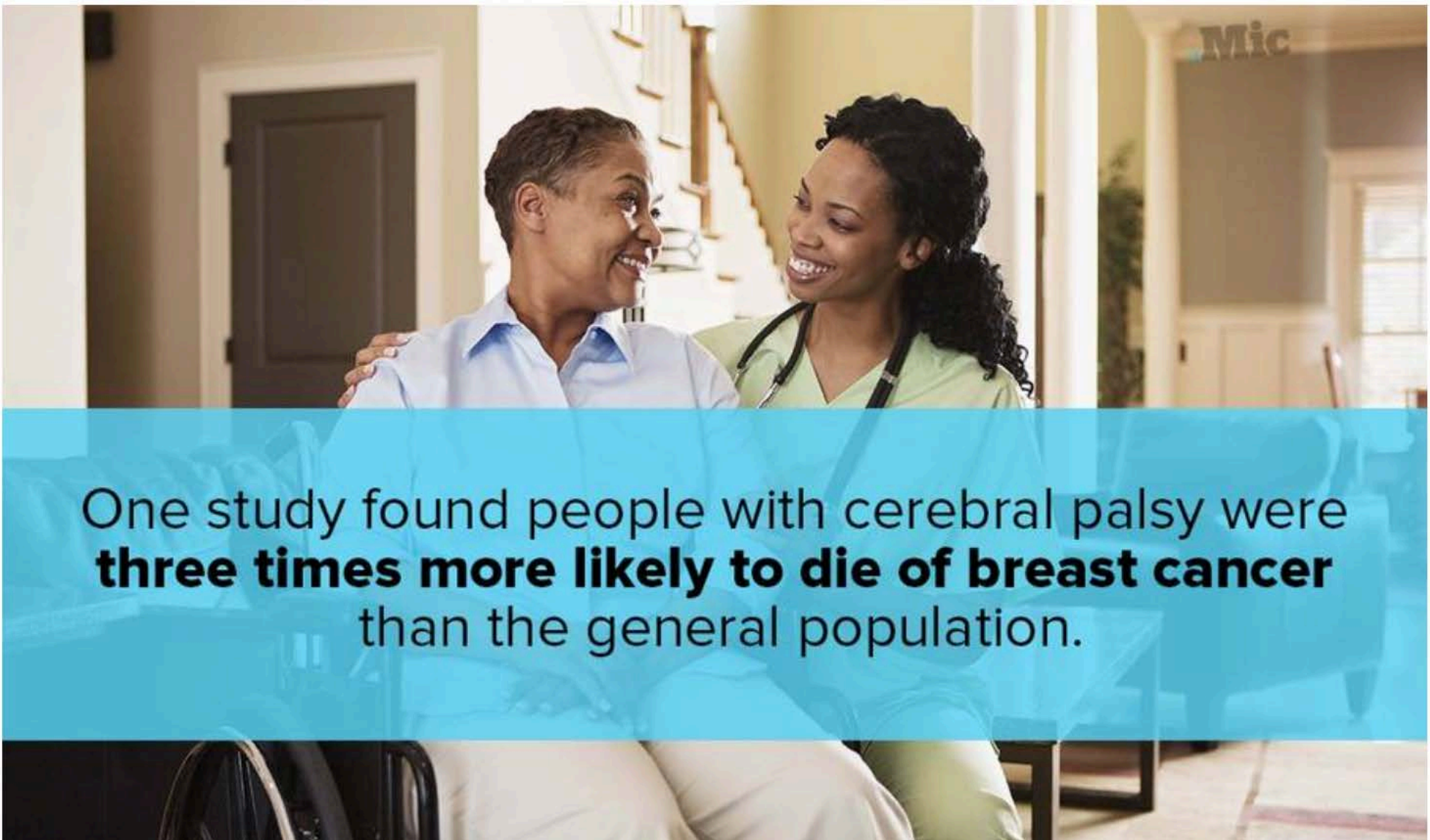
Percentage of Women 50-74 Years of Age Who Received a Mammogram in Past 2 Years

By Disability Status:



* CDC/NCHS. National Health Interview Survey Data, 2010.³

<https://www.cdc.gov/ncbddd/disabilityandhealth/breast-cancer-screening.html>



One study found people with cerebral palsy were **three times more likely to die of breast cancer** than the general population.

<https://mic.com/articles/134979/women-with-disabilities-are-more-likely-to-die-of-breast-cancer-here-s-why>

Strauss, D., Cable, W., & Shavelle, R. (January 01, 1999). Causes of excess mortality in cerebral palsy. *Developmental Medicine & Child Neurology*, 41, 9, 580-585.



Potential Mammography Issues for Women with Disabilities

- Women with disabilities may need more than one technician to help them access a mammogram machine
- WWD may not be able to stand for the amount of time required to complete the mammogram
- WWD may not understand what is happening to them or may fear the test beyond pain, discomfort, etc





Health Disparities

1. Women with disabilities are a medically underserved population;
2. This population is at an increased risk of breast cancer and significantly less likely to receive a (CBE) and recommended mammogram screenings, often leading to a later stage diagnosis impacting survival;
3. This population has more risk factors for getting breast cancer;
4. These health inequities are often due to physical, environmental, cultural and attitudinal barriers experienced by women of disabilities.



Screening for Women with Disabilities

- Women with disabilities are more likely to be diagnosed with larger tumors and late stage breast cancer.
- Women with disabilities are less likely to get regular clinical breast exams (when health care provider looks at and feels your breasts) and mammograms (x-rays of the breasts).



Why this Project is Important for WWD?

- Women with disabilities often believe mammography facilities are not accessible or welcoming to them
- Fear increased radiation exposure will give you cancer
- Mammogram painful – lack of training of technologists
 - Can they position me in the machine?



Breast cancer was just another obstacle I had to fight.

—DIANE, SURVIVOR

As a young mother, a spinal cord injury left Diane with a disability.

And at 40, she was first in her family to be diagnosed with breast cancer. She calls the cancer her wake-up call, and credits early detection with still being alive today.

Breast cancer is the most common cancer in women. And living with a disability doesn't make you immune.

If you are between the ages of 40 to 49, talk to your doctor about when and how often you should have a screening mammogram. If you are between the ages of 50 to 74, be sure to have a screening mammogram every two years.

BREAST CANCER SCREENING

THE RIGHT TO KNOW

For more information, visit
www.cdc.gov/RightToKnow
or call 1-800-CDC-INFO (232-4636)
1-888-232-6348 (TTY)



Centers for Disease
Control and Prevention
National Center on Birth Defects
and Developmental Disabilities



Our Study of Women with Disabilities & Mammography

- We surveyed women with disabilities who were over 40 or under 40 but were told to get a mammogram
- Our subjects:
 - 43% of the women had great difficulty with walking or climbing steps.
 - 11% had great difficulty with self-care
 - 95%+ had insurance coverage of some kind that covered mammograms
-



Findings

- 32%+ had not had a mammogram in the last 2 years:
 - 58% said they had no difficulty because of their disability
 - 30% said the mammogram was uncomfortable because of their disability
 - Almost 12% said they told the staff they would need accommodations in order to have a mammogram and the staff said accommodations would not be available
 - Almost 7% said the facilities were not accessible
 - Almost 7% had difficulty getting transportation to the facility



Findings

- Top reason for not getting a mammogram in the last 2 years was the *lack of an accessible machine 21%*
 - *Difficulty accessing the facility almost 16%*
 - *Almost 11% didn't know they needed to have one*




What Can You Do in Your Community?

- Raise awareness of the need to have a mammogram among women with disabilities. Lightning does strike twice.
- Women with disabilities are sexual beings like other women. Physicians need to be aware that women with disabilities have health care needs like other women
- Promote awareness of the need for accessible mammography facilities. (It is also the law under the Americans with Disabilities Act.)
- Promote AAHD's Assessment Guide to promote accessible mammography facilities



“Assessment Guide for Mammography Facilities”

Available on the AAHD Website






ACCESSIBILITY SELF-ASSESSMENT GUIDE FOR
MAMMOGRAPHY FACILITIES

FACILITY NAME _____

COMPLETED BY _____

AFFILIATE _____

PROJECT ACCESSIBILITY USA IS A COLLABORATIVE PARTNERSHIP BETWEEN THE
AMERICAN ASSOCIATION ON HEALTH AND DISABILITY AND THE
CENTER FOR DEVELOPMENT AND DISABILITY AT THE UNIVERSITY OF NEW MEXICO
WITH FUNDING PROVIDED BY SUSAN G. KOMEN FOR THE CURE.



Version 5.0 October 21st, 2013




“Assessment Guide for Mammography Facilities”


- Parking Lot Accessibility
- Building Accessibility
- Elevator Accessibility
- Ramp Accessibility
- Waiting Room Accessibility
- Mammography Suite Accessibility
- Mammography Equipment Accessibility
- Bathroom and Sink Accessibility



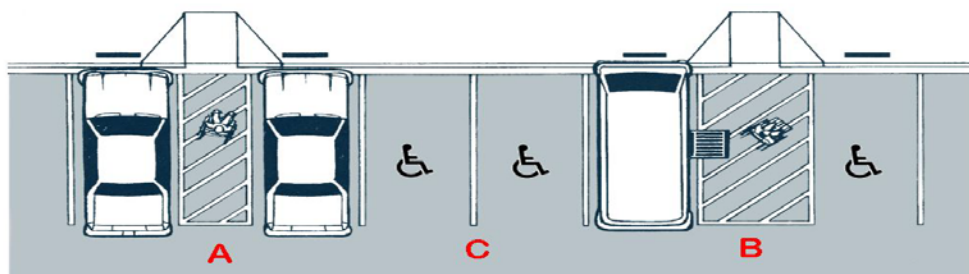
"Assessment Guide for Mammography Facilities"

Parking Lot Accessibility

1. Are the accessible parking spaces clearly marked on the pavement itself, with a sign  and notice of fine for use without proper placard? Yes ☐ No ☐
2. Are the accessible parking spaces the closest parking spaces to the accessible entrance of the facility? Yes ☐ No ☐
3. Are all of the accessible parking spaces and access aisles flat (no slope)? Yes ☐ No ☐
4. Does each accessible parking space have an adjacent striped access aisle as shown in the diagram below? Yes ☐ No ☐

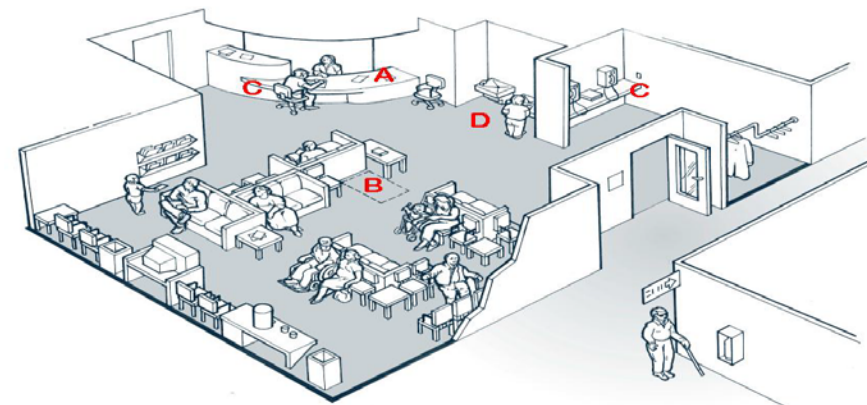
There are three kinds of accessible parking spaces: "car accessible" (5 foot wide aisle shared by two spaces) as in Example A below. "Van accessible" (spaces with an 8 foot wide access aisle adjacent to the car) as in Example B below and "handicap reserved" (spaces without adjacent loading space but marked with the sign on the  pavement) as in example C below.

5. How many car-accessible parking spaces are in your parking lot ("A" in the diagram below)?
6. How many ramp van accessible parking spaces are in your parking lot ("B" in the diagram below)?
7. How many handicap reserved spaces are there in your parking lot ("C" in the diagram below)?
8. How many parking spaces are there (total) in your parking lot?



Waiting Room accessibility

1. Is the opening in the main entry door to the reception/waiting area at least 36" wide? Yes ☐ No ☐
2. Are the tops of any work surfaces such as countertops, etc. ("A" in the diagram below):
 - A. a minimum of 28" from the floor? Yes ☐ No ☐
 - B. a maximum of 34" from the floor? Yes ☐ No ☐
3. Are there open floor spaces in the seating area where people with wheelchairs, scooters, strollers, or service animals can easily wait ("B" in the diagram below)? Yes ☐ No ☐
4. Is there at least 27" of "knee space" below work surfaces such as reception desks, telephone counters, etc. ("C" in the diagram below) so people using wheelchairs can fit them underneath? Yes ☐ No ☐
5. If there are water fountains in the waiting area ("D" in the diagram below), do they meet these requirements:
 - A. Is the water fountain in an alcove? Yes ☐ No ☐
 - B. For "high" water fountains (meant to be used while standing), is the spout no higher than 43" from the floor? Yes ☐ No ☐
 - C. For "low" water fountains (meant to be used while sitting), is the spout no higher than 36" from the floor? Yes ☐ No ☐
6. 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 ☐





“Guide to Interacting With Women with Disabilities for Facility Staff”



Project Accessibility Quick Guide To Interacting With People With Disabilities

People With All Types Of Disabilities

- ♦ Introduce yourself and offer a handshake. The person will tell you if they are not able to shake hands for some reason.
- ♦ Always ask before giving assistance.
- ♦ Speak directly to the person and not their attendant, interpreter, etc.
- ♦ Do not pet service animals without checking with the owner first.
- ♦ Use the Project Accessibility recommended intake questions to learn how to best serve your patient with a disability.

People With Mobility Disabilities

- ♦ Do not push or touch a person's wheelchair without their permission.
- ♦ Try to ensure that there is space in your waiting rooms for someone in a wheelchair to comfortably wait in their chair.

People With Cognitive Or Intellectual Disabilities

- ♦ Keep communication simple, using short sentences and completing one topic before moving to the topic.
- ♦ If possible, use pictures or other visibility aids.
- ♦ Ask if the person has any questions or if there is anything they would like for you to clarify.



PROJECT ACCESSIBILITY USA IS A COLLABORATIVE PARTNERSHIP BETWEEN THE AMERICAN ASSOCIATION ON HEALTH AND DISABILITY AND THE CENTER FOR DEVELOPMENT AND DISABILITY AT THE UNIVERSITY OF NEW MEXICO. FUNDING IS PROVIDED BY SUSAN G. KOMEN FOR THE CURE.

People With Psychiatric Disabilities

- ♦ Many people with psychiatric disabilities may become agitated or even seem angry when they are actually just confused; don't assume the person is violent or dangerous.
- ♦ Do not assume that they have a cognitive disability (e.g., mental retardation) as well. Speak to them as you would any other person.
- ♦ If someone with a psychiatric disability becomes upset or angry, calmly ask how you may assist them in getting their needs met.

People With Visual Disabilities

- ♦ Introduce yourself and anyone else who is present for the conversation.
- ♦ Offer to read information to a person when appropriate.
- ♦ If you are asked to guide someone, offer your arm, and then walk slightly ahead of them after they take your arm. Describe barriers in the way, such as steps, and announce which direction you will be turning. Never push or pull someone.
- ♦ Do not pet or distract their guide dog.

People With Hearing Disabilities

- ♦ Let the person establish their preferred method of communication for your conversation, such as lip reading, sign language or writing notes. Refer to the intake questions for further guidance on how to know in advance what the patient will require.
- ♦ Always speak directly to the person and not their interpreter.
- ♦ Do not raise your voice unless they request that you do so.

People With Speech Disabilities

- ♦ Be prepared for patients with speech disabilities to take longer to communicate with you.
- ♦ Do not interrupt or finish their sentences for them. Give them time!
- ♦ Ask one question at a time, giving them time to respond before moving on.
- ♦ Ask the patient to repeat themselves if you do not understand them.
- ♦ If the person uses any assistive technology devices, make sure they are always within the person's reach.



Recommend Our Online Training Course

- Working with women with disabilities:

Provides both clinicians and non-clinicians with useful, easy-to-use information about how to work effectively with women with a wide range of disabilities. The self-paced course is free, and can be completed on your own schedule. You can also get a certificate of completion.



Division of Disability and Health Policy

CDD Home

Division of Disability and Health Policy

About Us

Division Staff

➤ **Programs and Projects**



[Center for Development and Disability](#)

2300 Menaul Blvd NE
Albuquerque, NM 87107

Phone: (505) 272-3000
Fax: (505) 272-2014

[UNM](#) > [CDD](#) > [DHPD](#)

Project Accessibility USA

[Module 1](#): Introduction and Overview

[Module 2](#): The Best Possible Care

[Module 3](#): Interacting with Women with Disabilities

[Module 4](#): Basic Issues and Facility Accessibility

[Module 5](#): Simple Ideas to Ensure a Successful Mammography for Women With Disabilities

[Resources](#): Project Accessibility USA Learning Portal

Act Now

[Contact DDSD Web Portal Support](#)
[Contact DDSD Training Unit](#)

Resources

[Online Courses](#)
[Training Calendar](#)
[DDSD Training Database](#)

<http://www.cdd.unm.edu/dhpd/programs/learnportal/courses/ProjectAccess.html>



AAHD & Breast Health for Women with Disabilities

- www.aahd.us - AAHD website
- <https://www.aahd.us/initiatives/susan-g-komen-grants>

Fact Sheets, Posters, Tip Cards, Mammography Facility Assessment, Client Reminders



Contact Information

Roberta Carlin, MS, JD
American Association on Health and Disability
110 N. Washington Street, Suite 328J
Rockville, MD 20850

rcarlin@aahd.us

301-545-6140 ext. 206

www.aahd.us

Barbara L. Kornblau, JD, OTR/L
BarbaraKornblau@gmail.com
Cell 305-778-0002