



American Association on Health and Disability (AAHD)

**SCI ISIG Women's Health Task Force Meeting
February 27th, 2020**

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**American Association on Health and Disability
(AAHD)**



Webinar Overview

- AAHD Overview
- Health Disparities and Breast Health
- AAHD Projects on Mammography Accessibility
- Overview of Project Activities
- Moving Forward



American Association on Health and Disability (AAHD)

AAHD is a cross-disability national organization 501 (c) 3 dedicated to promote health and wellness initiatives for people with disabilities. AAHD accomplishes its mission through research, education, public policy and knowledge translation

- Reduce Health Disparities
- Advocate for Community Inclusion
- Promote Full Accessibility
- Integrate Disability into Public Health Agenda

Disability and Health Journal – www.disabilityhealthjnl.com



AAHD Overview -Members

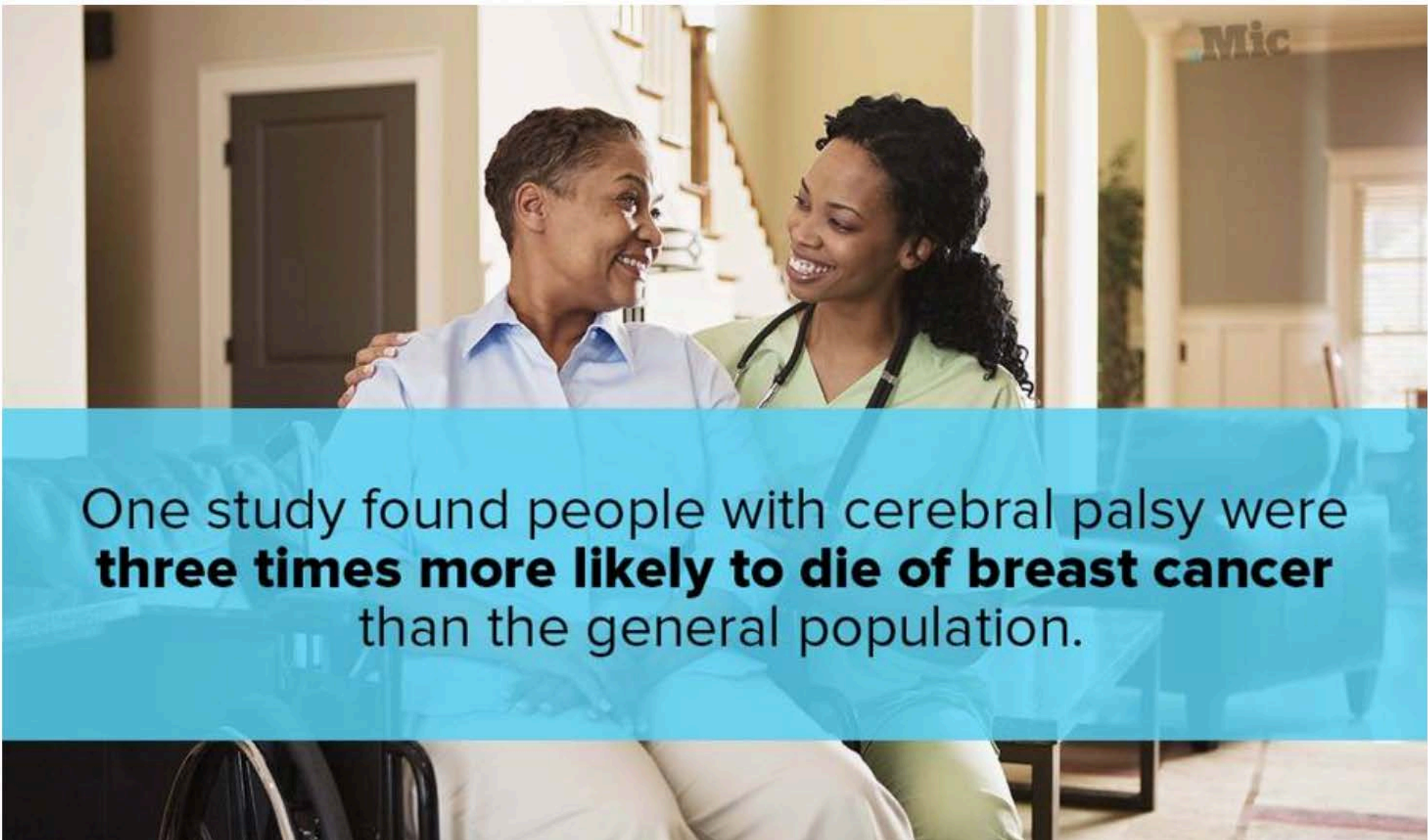
- People with Disabilities
- Caretakers
- Disability Researchers
- Public Health Professionals
- Disability Organizations
- Policy Analysts
- Healthcare Professionals



Lightning 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.



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.



African-American & Hispanic/Latina Women & Breast Cancer

- African-American women tend to be diagnosed at a younger age (59) than white women (63); most common cancer among African American women;
- Breast cancer mortality is nearly 40% higher in African American women than white women;
- African American and Hispanic/Latina women more likely to be diagnosed with larger tumors and late stage breast cancer.

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.



“The Double Burden”

- “Aside from public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic disparities, 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 Equity for Minority Persons with Disabilities: A Statement of Principles and Recommendations (July 2011)



Disability - Based Health Disparities

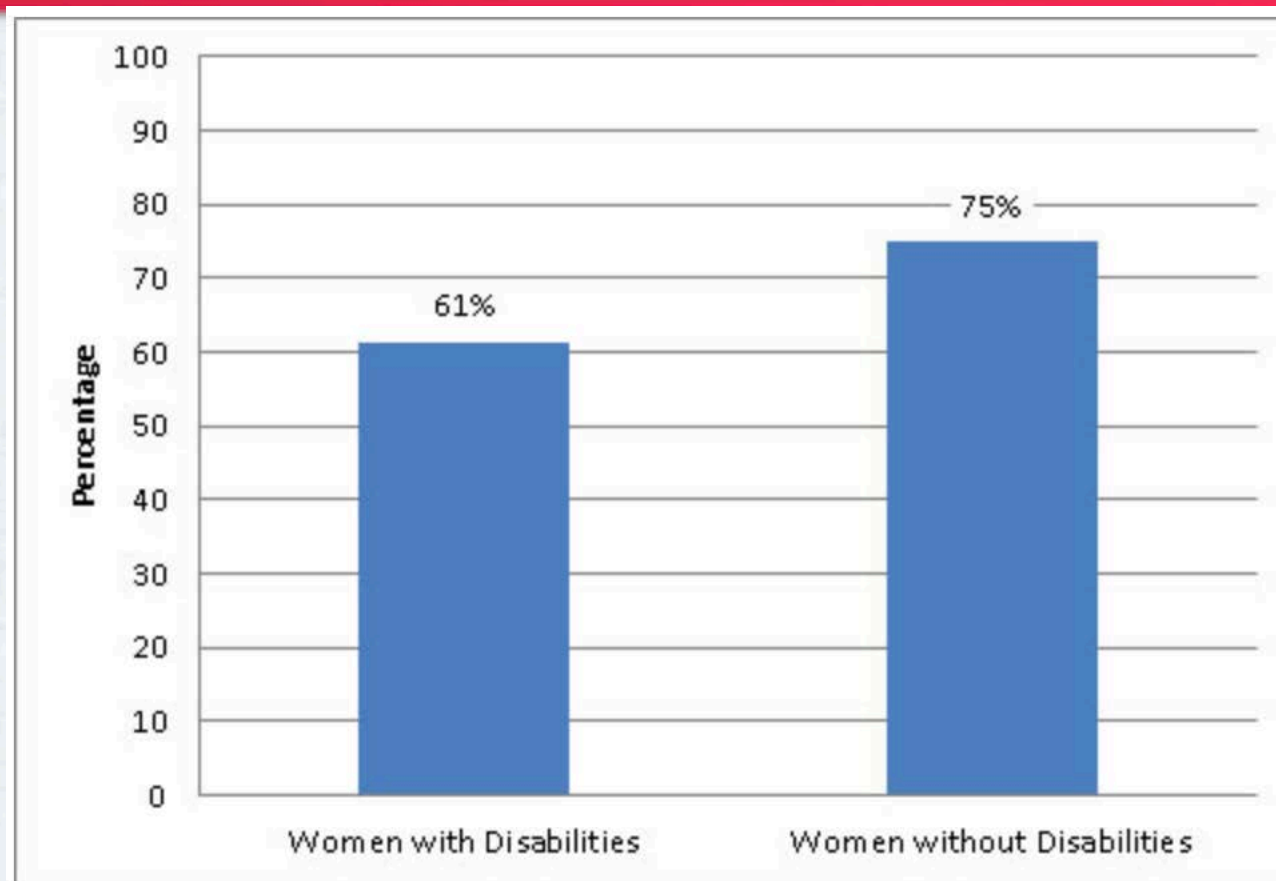
According to HealthyPeople.gov (2014) women with disabilities are less likely to have had a mammogram or CBE in the past two years, often leading to larger tumors and later stage breast cancer impacting survival

Overall, women with disabilities receive mammograms at lower rates than nondisabled women – rates have not changed over time (NHIS).



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



Disability-Based Health Disparities

Multiple reasons for health disparities and health inequities between women with disabilities and women without disabilities 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).



Disability-Based Health Disparities

- **Why the delay in mammography screening?**
 - Environmental Barriers
 - Attitudinal Barriers
 - Physical Barriers
 - Cultural Barriers
 - Communication Barriers
 - Fear of Procedure/Radiation/Accessibility
 - Confusing/Conflicting Recommendations



AAHD & Susan G. Komen Projects

- 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 & Susan G. Komen Projects

- 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”*** – A National Program
- 2016 - 2019 ***“Breast Cancer Awareness for Women with Disabilities: Lightning Can Strike Twice”*** (Washington DC, Wards 2, 5,7, & 8)



AAHD & Susan G. Komen Deliverables

- Develop Facility Assessment Tool to Assess Accessibility of FDA Approved Mammography Facilities
- Conduct On-Site Mammography Assessments of Facilities; Provided Confidential Report
- Host Small Educational Workshops for Women with Disabilities and Community Organizations
- Develop On-line Training Modules and Resource Portal
- Provide Coaching Sessions for Women with Disabilities



AAHD & Susan G. Komen Deliverables

- Podcast – “Self Advocacy and Women with Disabilities”
- Provide Technical Assistance
- Develop Fact Sheets, Tip Cards, Client Reminders, Posters
- Project Partners

Association of Public Health Nurses (APHN)

UNM School of Medicine, Center for Development and Disability;

Susan G. Komen and Komen Grantees

Community-Based Organizations



Deliverable: Assessment Guide for Mammography Facilities



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

Available from AAHD or on AAHD website at www.aahd.us




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**



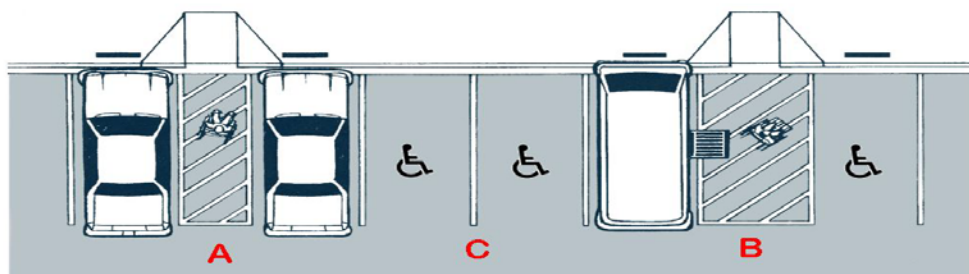
“Assessment Guide for Mammography Facilities”

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

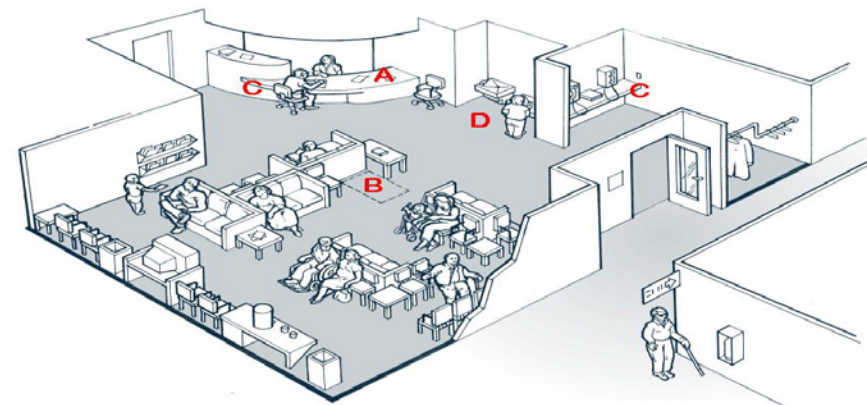
There are three kinds of accessible parking spaces: “car accessible” (5 foot wide aisle shared by two spaces) as in Example A below. “Van accessible” (spaces with an 8 foot wide access aisle adjacent to the car) as in Example B below and “handicap reserved” (spaces without adjacent loading space but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



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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.



On-Line Training Modules

- Module 1: Introduction & Overview of Navigating On-Line Modules
- Module 2: Mammography Screening
- Module 3: Interacting with Women with Disabilities/Disability Etiquette
- Module 4: Basic Facility Accessibility
- Module 5: A, B, C's of a Successful Visit



Project Findings

- 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?





Testimonials from Women with Disabilities - Numerous Projects

- “I won’t be able to get a mammogram because the facility won’t be accessible.”
- “Getting a mammogram will hurt.” “Getting my mammogram did hurt .”
- “The staff was never nice to me-so, I stopped going.”
- “Cancer treatment makes you sick. I have no one to help me. I will be alone”
- “Technologists are poorly trained.”
- There is no point in getting a mammogram, if they find something it will be too late to do anything about it anyway.”
- “Getting a mammogram will expose me to radiation and can give me breast cancer.”
- “Any changes in my mammogram mean I have breast cancer.”



Potential Mammography Issues for Women with Disabilities

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





AAHD & FAMU Project -Methodology

- Descriptive Study n= 80 – self-identified women with disabilities over age 40; IRB Approved
- Recruited from email lists, Twitter, Facebook, disability-specific Facebook groups
- Data collected via online survey using Survey Monkey – descriptive statistics completed



AAHD & FAMU Results

- 37% reported lack of physical access was a barrier
- Over 32% reported other reasons such as parking and staff attitudes
- 10.5% reported transportation and parking



AAHD & FAMU Results

- 30% said the mammogram was uncomfortable because of their disability
- Almost 12% reported a lack of accommodations
- 21% reported there was no accessible mammography machine for their use
- 3% reported staff unable to accommodate their needs



AAHD & FAMU Results

- 32%+ had not had a mammogram in the last 2 years:
 - 11% did not know they needed a mammogram
 - 16% had difficulty accessing the facility

Top reason for not getting a mammogram in the last 2 years was the *lack of an accessible machine 21%*



Project Conclusions

- *Women with disabilities continue to face numerous barriers to mammography and breast cancer screening despite legal and policy changes resulting from the ADA.*
- *Self advocacy is a powerful tool that women with disabilities can use to advocate to eliminate barriers to their breast health needs!*



What Can Be Done to Change Practice and Policy?

- Raise awareness of healthcare providers on the importance of accessible breast health screenings.
- Educate women about importance of self advocacy.
- Promote awareness of the need for accessible mammography facilities. (It is also the law under the Americans with Disabilities Act).
- Educate and encourage providers to adhere to federal guidelines in the procurement of diagnostic equipment as stated in the Standards for Accessible Medical Diagnostic Equipment www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking



Advocacy: Numbers Represent Power

- National Breast Health Coalition for Women with Disabilities – AAHD Initiative
- Georgetown Breast Cancer Advocates (GBCA) – Georgetown University



Resources

AAHD Website

www.aahd.us

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



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