

American Association on Health & Disability

110 N. Washington Street Suite 328-J Rockville, MD 20850 Tel: 301-545-6140 Fax: 301-545-6144 Website: www.aahd.us

"PROJECT ACCESSIBILITY: REMOVING BARRIERS FOR WOMEN WITH DISABILITIES" SUSAN G. KOMEN FOR THE CURE® GRANT'S

DISABILITY AND CULTURAL AWARENESS COMPENDIUM FOR MAMMOGRAPHY FACILITIES (2013)

Table of Contents

(Numeral Corresponds with Tab Number)

- 1. "PROJECT ACCESSIBILITY: REMOVING BARRIERS FOR WOMEN WITH DISABILITIES" (A REPLICABLE HEALTH PROMOTION PROGRAM)-- SURVEY INSTRUMENTS, EVALUATION INSTRUMENTS, AND PROGRAM MATERIALS
 - Fact Sheet/Brochure: "Susan G. Komen for the Cure® and American Association on Health & Disability (AAHD) Work Toward Increasing Mammography Screening for Women with Disabilities in the D.C. Metro Area," American Association on Health and Disability
 - Fact Sheet/Brochure: "Tips for Mammography Staff: How to Serve Women with Disabilities More Effectively," American Association on Health and Disability
 - Fact Sheet/Brochure: "Tips for Women with Disabilities: Getting Your Mammogram," American Association on Health and Disability (in English and in Spanish)
 - "Introductory Letter to Mammography Facilities," American Association on Health and Disability
 - "Mammography Accessibility Facility Survey," American Association on Health and Disability
 - "Suggested Intake Questions on Disabilities When Scheduling a Mammography Appointment," American Association on Health and Disability
 - "Post Survey Evaluation," American Association on Health and Disability
 - "Introductory Letter for Breast Cancer Screening Survey for Women with Disabilities," American Association on Health and Disability
 - "Breast Cancer Screening Survey for Women with Disabilities," American Association on Health and Disability

- Governmental Groups on People with Disabilities in the National Capitol Area (Washington, D.C. and Six Surrounding Areas Targeted by Susan G. Komen for the Cure®), American Association on Health and Disability, 2009
- The Centers for Disease Control and Prevention (CDC) Right to Know Campaign, 2009

http://www.cdc.gov/ncbddd/disabilityandhealth/righttoknow/overview.html

- "Facts for Life: Women with Disabilities," Susan G. Komen for the Cure®, developed in Collaboration with the Health Communication Research Laboratory at Saint Louis University, 2008 http://ww5.komen.org/uploadedFiles/Content_Binaries/806-03752a.pdf
- "Lifting the Barriers: Women with Disabilities Face a Host of Obstacles to Mammography Screening. Ease Burdens of the Process" by Sarah Long, Advance for Imaging and Radiation on-line article, 2008
 http://enterprise-imaging-radiology-management.advanceweb.com/Article/Lifting-the-Barriers.aspx
- "Health Exams": Chapter 6 from <u>A Health Handbook for Women with Disabilities</u> by Jane Maxwell, Julia Watts Belser, and Darlena David, 2007

2. MEETING THE NEEDS OF PEOPLE WITH DISABILITIES BY INTERACTING AND COMMUNICATING EFFECTIVELY

- "Communicating With and About People with Disabilities", United States Department of Labor. 2012. http://www.dol.gov/odep/pubs/fact/comucate.htm#.UJ10dlatZhs
- "People First: A Guide to Interacting with People with Disabilities DHS-4151", Illinois Department of Human Services. 2012. http://www.dhs.state.il.us/page.aspx?item=32276
- "Telehealth for persons with severe functional disabilities and their caregivers: facilitating self-care management in the home setting". Psychol Serv. 2012 May;9(2):144-62. Abstract
- "Non-verbal communication between Registered Nurses Intellectual Disability and people with an intellectual disability: an exploratory study of the nurse's experiences". Part 1. J Intellect Disabil. 2012 Mar;16(1):61-75. Abstract
- "The role of the International Classification of Functioning, Disability, and Health and quality criteria for improving assistive technology service delivery in Europe". Am J Phys Med Rehabil. 2012 Feb;91(13 Suppl 1):S55-61. Abstract
- "Communicating with and About People with Disabilities. Disabled Person", 2012. https://www.disabledperson.com/communicating-with-pwd

- "Communicating with people with disabilities" a video tutorial. National Inclusion Service Project, 2012. http://www.serviceandinclusion.org/index.php?page=video_tut1
- "How To Communicate With People With Disabilities. Thirteen WNET New York Public Media", 2012. http://www.thirteen.org/rolling/building-a-more-accessible-world/how-to-communicate-with-people-with-disabilities/11/#.UMoEWtVqPcs
- "Program Development Associates: The Professional's Choice for Disability and Diversity Resources". Retrieved December 13, 2012 from http://www.disabilitytraining.com/product-list.php?Communication-pg1-cid41.html
- "Workplace Communication Tips for People Living With Disabilities". Hydrocephalus Association, 2012. http://www.hydroassoc.org/ha-updates/workplacecommunication-tips-for-people-living-with-disabilities/
- "Fold-A-Board communication device". Top Stroke Rehabil. 2011 Jul-Aug;18(4):367-71. Abstract
- "Opportunities for people with disabilities in the virtual world of Second Life". Rehabil Nurs. 2010 Nov-Dec;35(6):254-9. Abstract
- "Exploring communication assistants as an option for increasing communication access to communities for people who use augmentative communication". Augment Altern Commun. 2010 Mar;26(1):48-59. Abstract
- "Communicating about the experience of pain and fatigue in disability". Qual Life Res. 2010 Mar;19(2):243-51. Abstract
- "Disability Etiquette: Tips on Interacting with People with Disabilities" by United Spinal Association, 2008 http://www.unitedspinal.org/disability-etiquette/
- "Environmental factors that influence communication between people with communication disability and their healthcare providers in hospital: a review of the literature within the International Classification of Functioning, Disability and Health (ICF) framework". Int J Lang Commun Disord. 2008 Nov-Dec;43(6):601-32. Abstract
- "To the Health Worker: Learning about Disability" from <u>A Health Handbook for Women with Disabilities</u> by Jane Maxwell, Julia Watts Belser, and Darlena David, 2007
- "Removing Barriers to Health Care: A Guide for Health Professionals" by R.L. Mace, 1998, Reprinted in 2007 http://www.fpg.unc.edu/~ncodh/pdfs/rbhealthcare.pdf

3. DOMESTIC AND INTERNATIONAL RESOURCES ON DISABILITIES

(We encourage the reader to visit the URLs in the comprehensive lists of websites below that focus on issues pertaining to disability and health; we offer these lists as guides to

further information. We hope you will contact AAHD if you know of any additional resources you would like us to consider including in the domestic listing developed by AAHD.)

- World Report on Disability, World Health Organization, 2012
 http://www.who.int/disabilities/world_report/2011/report/en/index.html
- Disabilities and Rehabilitation: Information Resources, World Health Organization, 2012 http://www.who.int/disabilities/publications/en/index.html
- Disability in Africa Region: Publications and Reports, The World Bank, 2012 http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTI ON/EXTDISABILITY/0,,contentMDK:20183406~menuPK:417328~pagePK:14895 6~piPK:216618~theSitePK:282699,00.html
- Disability Information Benefits, Facts and Resources for Persons with Disabilities, Disabled World News - Disabled World category on disability offers news and articles concerning disabilities including health issues: http://www.disabledworld.com/disability/#ixzz2DRrz7VPu
- Disability News Stories and Information on Disabilities, Disabled World Towards Tomorrow, 2012 http://www.disabled-world.com/news/
- The Canadian Disability Resource Database, 2012 http://canadian-disability-resources.ca/
- Christopher and Dana Reeve Foundation: Paralysis Resource Center Canadian Disability Resources, 2012.
 http://www.christopherreeve.org/atf/cf/%7B3d83418f-b967-4c18-8ada-adc2e5355071%7D/Canada%206-09.PDF
- Disability Resources and Organizations Links, Ability Magazine, 2012 http://abilitymagazine.com/links.html
- Joint position paper on the provision of mobility devices in less resourced settings,
 World Health Organization and United Stated Agency International Development,
 2011 http://apps.who.int/iris/bitstream/10665/44780/1/9789241502887 eng.pdf
- Domestic Disability Resources and Organizations, The American Association on Health and Disability, 2009
 http://www.aahd.us/resource-center/disability-links/disability-organizations/
- International Organizations, Books and Other Printed Materials, and Internet-Based Resources <u>Health Handbook for Women with Disabilities</u> by Jane Maxwell, Julia Watts Belser, and Darlena David, 2007

4. RESEARCH ON WOMEN WITH DISABILITIES AND BREAST HEALTH

- "Cervical and breast cancer-screening knowledge of women with developmental disabilities". **Intellect Dev Disabil.** 2012 Apr;50(2):79-91. Abstract
- "Breast cancer screening barriers and disability". Rehabil Nurs. 2012 Mar-Apr;37(2):74-9. Abstract
- "Florida mammographer disability training vs needs". Radiol Technol. 2012 Mar;83(4):337-48. Abstract
- "Access to cancer screening for women with mobility disabilities". J Cancer Educ. 2012 Mar;27(1):75-82. Abstract
- "The assessment of the likelihood of mammography usage with relevant factors among women with disabilities". Res Dev Disabil. 2012 Jan-Feb;33(1):136-43. Epub 2011 Oct 4. Abstract
- "Disparities in routine breast cancer screening for medicaid managed care members with a work-limiting disability". Medicare Medicaid Res Rev. 2011 Nov 4;1(4). Abstract
- "Implications of Mobility Impairment on the Diagnosis and Treatment of Breast Cancer". J Womens Health (Larchmt). 2011 January; 20(1): 45–52
- "Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective". Eur J Cancer Care (Engl). 2011 May;20(3):412-20. doi: 10.1111/j.1365-2354.2010.01221.x. Epub 2010 Sep 6. Abstract
- "Predictors of mammography use in older women with disability: the patients' perspectives". Med Oncol. 2011 Dec;28 Suppl 1:S8-14. Epub 2010 Sep 21. Abstract
- "Disability and health-related quality of life after breast cancer surgery: relation to impairments". South Med J. 2010 Jan;103(1):37-41. Abstract
- "Breast awareness within an intellectual disability setting". Eur J Oncol Nurs. 2010 Sep;14(4):328-36. Epub 2010 May 20. Abstract
- "Expected values for steps/day in special populations". Prev Med. 2009 Aug;49(1):3-11. Epub 2009 May 4. Abstract
- "Managed care enrollment and chronically disabled women with breast cancer". Am J Manag Care. 2008 Aug;14(8):514-20. Abstract
- "State-Level Differences in Breast and Cervical Cancer Screening by Disability Status: United States, 2008." Womens Health Issues. 2009 Nov-Dec;19(6):406-14. Abstract
- "Barriers to Adherence to Screening Mammography among Women with Disabilities." <u>Am J Public Health</u>. 2009 Oct 15. [Epub ahead of print] Abstract
- "Repeat Mammography Screening Among Unmarried Women with and without a Disability." Womens Health Issues. 2009 Sep 21. [Epub ahead of print] Abstract

- "Breast and Cervical Cancer Screening Practices among Disabled Women Aged 40-75: Does Quality of the Experience Matter?" <u>J Womens Health (Larchmt)</u>. 2008 Oct;17(8):1321-9. Abstract
- "Understanding Barriers to Participation in Mammography by Women with Disabilities." American Journal of Health Promotion. 2008; 22(6): 381-5. Abstract
- "Disability and Receipt of Clinical Preventive Services among Women." Womens Health Issues. 2006; 16(6): 286-296. Abstract
- "The Influence of Type and Severity of Mental Illness on Receipt of Screening Mammography." <u>J Gen Intern Med.</u> 2006; 21(10): 1097-1104. Abstract
- "Disparities in Breast Cancer Treatment and Survival for Women with Disabilities". Ann Intern Med. 2006 November 7; 145(9): 637–645.
- "Women with cerebral palsy and breast cancer screening by mammography". Arch Phys Med Rehabil. 2006 Feb;87(2):304-7. Abstract
- "Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities". Fam Community Health. 2006 Jan-Mar;29(1 Suppl):35S-43S. Abstract
- "Access to breast cancer screening services for women with disabilities". J Obstet Gynecol Neonatal Nurs. 2005 Jul-Aug;34(4):453-64. Abstract
- "Women with disabilities: general practitioners and breast cancer screening". Am J Prev Med. 2005 Feb;28(2):215-20. Abstract

5. WOMEN FROM VARIOUS CULTURES AND BREAST HEALTH

- A Listing of Susan G. Komen for the Cure® Breast Self-Awareness (BSA) Cards in a Variety of Languages
 http://www.shopkomen.com/cart.php?m=product_list&c=99
- "Spiritual well-being and quality of life in Iranian women with breast cancer undergoing radiation therapy". **Support Care Cancer.** 2012 Nov 10. Abstract
- "Understanding barriers to Malaysian women with breast cancer seeking help". **Asian Pac J Cancer Prev.** 2012;13(8):3723-30. Abstract
- "Health belief model and practice of breast self-examination and breast cancer screening in Iranian women". Breast Cancer. 2012 Sep 19. Abstract
- "Development of the Thai breast cancer belief scale for Thai immigrants in the United States". **J Nurs Meas.** 2012;20(2):123-41. Abstract
- "Breast cancer in Pacific Islander women: overcoming barriers to screening and treatment". **Nurs Womens** Health. 2012 Feb-Mar;16(1):26-35. Abstract

- "The relationship between religiosity and cancer screening among Vietnamese women in the United States: the moderating role of acculturation". Women Health. 2012;52(3):292-313. Abstract
- "Knowledge, attitudes, beliefs, behaviour and breast cancer screening practices in Ghana, West Africa". Pan Afr Med J. 2012;11:28. Epub 2012 Feb 17.
- "Breast cancer screening practices among Asian Americans and Pacific Islanders". Am J Health Behav. 2012 Sep;36(5):711-22. Abstract
- "Social determinants of breast cancer screening in urban primary care practices: a community-engaged formative study". Womens Health Issues. 2012 Sep;22(5):e429-38. Abstract
- 15 October Breast Health Day: Join the 2012 Campaign "Make Good Choices For Your Breast Health". Retrieved December 23, 2012 from http://www.breasthealthday.org/media-center/2012/press-release
- Breast cancer: prevention and control. World Health Organization. Retrieved December 28, 2012 from http://www.who.int/cancer/detection/breastcancer/en/index.html
- Sample Susan G. Komen for the Cure® Breast Self-Awareness (BSA) Cards in a Variety of Languages (in Arabic, Chinese, English, French, Hindi, Japanese, Korean, Large Print English, Large Print Spanish, Russian, Spanish, and Vietnamese and geared toward African Americans), 2009 http://www.shopkomen.com/cart.php?m=product_list&c=99
- "Facts for Life: Racial & Ethnic Differences," Susan G. Komen for the Cure®, developed in Collaboration with the Health Communication Research Laboratory at Saint Louis University, 2009
 - http://ww5.komen.org/uploadedFiles/Content_Binaries/806-373a.pdf
- "Determinants of the use of breast cancer screening among women workers in urban Mexico". Prev Chronic Dis. 2008 Apr;5(2):A50. Abstract

6. MEETING THE NEEDS OF PEOPLE FROM VARIOUS CULTURES BY INTERACTING AND COMMUNICATING EFFECTIVELY

- "The Compelling Need for Cultural and Linguistic Competence" from the Georgetown University Center for Child & Human Development's National Center for Cultural Competence
 - http://www11.georgetown.edu/research/gucchd/nccc/foundations/need.html
- Information on CyraCom, a provider of language services http://www.cyracom.com/About/
- "Communication as a mechanism for cultural integration". Nonlinear Dynamics Psychol Life Sci. 2013 Jan;17(1):87-105. Abstract

- Communication Matters: Communicating Effectively With Culturally and Linguistically Diverse Families. Communiqué. 2012 http://www.nasponline.org/publications/cq/mocq368commmatters.aspx
- Cultural Barriers to Effective Communication. Buzzle, 2012 http://www.buzzle.com/articles/cultural-barriers-to-effective-communication.html
- "Building Relationships with People from Different Cultures". From The Community Toolbox website, 2012 http://ctb.ku.edu/en/tablecontents/sub_section_main_1170.aspx
- Think Cultural Health. Advancing Health Equity at Every Point of Contact. From the Office
 of Minority Health Website, 2012
 https://www.thinkculturalhealth.hhs.gov/Content/communication_tools.asp
- Cultural Insights Communicating with Hispanics/Latinos. CDC, Office of the Associate Director for Communication 2012 http://www.cdc.gov/healthcommunication/Audience/AudienceInsight_CulturalInsights.pdf
- Culture, Language and Health Literacy. HRSA, 2012 http://www.hrsa.gov/culturalcompetence/index.html
- Clear Communication. A NIH Health Literacy Initiative. NIH, 2012 http://www.nih.gov/clearcommunication/culturalcompetency.htm
- "Linguistic Competence" from the Georgetown University Center for Child & Human Development's National Center for Cultural Competence, 2009 http://www11.georgetown.edu/research/gucchd/nccc/documents/Definition%20of%20Lingui stic%20Competence.pdf
- "The Voice on the Other End of the Phone" by Nataly Kelly, <u>Health Affairs</u>, Volume 27, No. 6, 2008 http://content.healthaffairs.org/cgi/reprint/27/6/1701.pdf
- "Language Differences as a Barrier to Quality and Safety in Health Care: The Joint Commission Perspective". J Gen Intern Med. 2007 November; 22(Suppl 2): 360–361. Abstract
- "A Call to Action: The Role of Health Literacy in Reducing Health Disparities" by Dr.
 Harold Freeman, presented at Surgeon General's Workshop on Improving Health Literacy,
 http://www.surgeongeneral.gov/topics/healthliteracy/panel2.htm
- "Lost in Translation: Language Barriers, Literacy, Communication, and Quality in Health Care" by Dr. Glenn Flores, presented at Surgeon General's Workshop on Improving Health Literacy, 2007 http://www.surgeongeneral.gov/topics/healthliteracy/panel2.htm
- "What is Cultural Competency?" from the Office of Minority Health website, 2005 http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=11

7. RESOURCES ON CULTURAL COMPETENCY

(We encourage the reader to visit the URLs in the comprehensive list of websites below that focuses on issues pertaining to cultural competency and health; we offer this list as a guide to further information. We hope you will contact AAHD if you know of any additional resources you would like us to consider including in this listing developed by AAHD.)

- Cultural Competency. CDC National Prevention Education Network, 2012 http://www.cdcnpin.org/scripts/population/culture.asp
- Where can I learn more about cultural competency? NIH, 2012
 http://www.nih.gov/clearcommunication/culturalcompetency.htm
- Cultural Competence Resources. Center for Effective Collaboration and Practice, 2012 http://cecp.air.org/cultural/resources.htm
- The Office of Minority Health, 2012
 http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=1&lvlID=3
- Cultural Competency and Minority Health Resources. American Association of Clinical Endocrinologists, 2012 https://www.aace.com/resources/cultural-competency-and-minority-health
- National Center for Cultural Competence, 2012 http://nccc.georgetown.edu/
- Culture, Language and Health Literacy Resources. HRSA, 2012 http://www.hrsa.gov/CulturalCompetence/general.html
- Cultural Competence. Society for Human Resource Management, 2012
 http://www.shrm.org/hrdisciplines/Diversity/Pages/MorePage.aspx?gid=g_94f9764b_f1
 0c_4d9a_a4a1_5f52defd566a&t=%3b130%3b&u=&h=Cultural+Competence&r=%2fh
 rdisciplines%2fDiversity%2fPages%2fcuturalcomp.aspx&so=DateTime&ao=0
- A Listing of Cultural Competency Resources and Organizations, The American Association on Health and Disability, 2009 http://www.aahd.us/resource-center/disability-links/cultural-competency/

8. RESEARCH ON CULTURAL COMPETENCY AND BREAST HEALTH

- "Challenges and implementation of a women's breast health initiative in rural Kashmir". <u>Breast</u>. 2011 Apr;20 Suppl 2:S46-50. Epub 2011 Feb 15. Abstract
- "Development and evaluation of a web-based breast cancer cultural competency course for primary healthcare providers." BMC Med Educ. 2011; 11: 59.

- "Using community-based participatory research to ameliorate cancer disparities." <u>Health</u> **Soc Work.** 2010 Nov;35(4):302-9. Abstract
- "Assess the effects of culturally relevant intervention on breast cancer knowledge, beliefs, and mammography use among Korean American women". **J Immigr Minor** Health. 2010 Aug;12(4):586-97. Epub 2009 Apr 17
- "Barriers to Breast Cancer Screening Among Haitian Immigrant Women in Little Haiti, Miami." <u>J Immigr Minor Health.</u> 2010 Jan 21. [Epub ahead of print] Abstract
- "Randomized Trial of a Lay Health Advisor and Computer Intervention to Increase Mammography Screening in African American Women." <u>Cancer Epidemiol Biomarkers Prev.</u> 2010 Jan;19(1):201-10.
- "Tailored Lay Health Worker Intervention Improves Breast Cancer Screening Outcomes in Non-Adherent Korean-American Women." <u>Health Educ Res.</u> 2009 Apr;24(2):318-29. Epub 2008 May 7. Abstract
- "Barriers and Facilitators Related to Mammography Use among Lower Educated Mexican Women in the USA." Soc Sci Med. 2009 Mar;68(5):832-9. Epub 2009 Jan 17. Abstract
- "Pre- and postintervention differences in acculturation, knowledge, beliefs, and stages of readiness for mammograms among Korean American women". **Oncol Nurs Forum.** 2009 Mar;36(2):E80-92.
- "Perspectives of African American, Amish, Appalachian And Latina women on breast and cervical cancer screening: implications for cultural competence". J Health Care Poor Underserved. 2008 Feb;19(1):56-74.
- "A critical review of theory in breast cancer screening promotion across cultures". **Annu Rev Public Health.** 2008;29:351-68.
- "Development and Evaluation of a Culturally Tailored Educational Video: Changing Breast Cancer-Related Behaviors in Chinese Women." <u>Health Educ Behav.</u> 2008 Dec;35(6):806-20. Epub 2007 Jun 29. Abstract
- "Designing Culturally and Linguistically Appropriate Health Interventions: The 'Life Is Precious' Hmong Breast Cancer Study." <u>Health Educ Behav.</u> 2007 Feb;34(1):140-53. Epub 2006 May 31. Abstract
- "Patient Satisfaction with Different Interpreting Methods: A Randomized Controlled Trial." <u>J</u> Gen Intern Med. 2007 Nov;22 Suppl 2:312-8. Abstract
- "Culturally competent training program: a key to training lay health advisors for promoting breast cancer screening. <u>Health</u> **Educ Behav.** 2007 Dec;34(6):928-41. Epub 2007 Oct 26. Abstract
- "Considering the culture of disability in cultural competence education. **Acad Med.** 2005 Jul;80(7):706-12. Abstract

In binder pockets:

Front:

- Pamphlet: "Breast Health Care: Easy to Read, Easy to Understand," North Carolina Office on Disability and Health, 2009 projects.fpg.unc.edu/~ncodh/pdfs/BreastHealthCare Web.pdf
- "Tips For Women With Disabilities: Getting Your Mammogram": an audio CD by the American Association on Health and Disability, 2009
- "A Guide to Disability Rights Laws" by the U.S. Department of Justice Civil Rights Division, September, 2006
 www.ada.gov/cguide.htm
- "The Americans with Disabilities Act: Questions and Answers" by the U.S. Department of Justice Civil Rights Division and the Equal Employment Opportunity Commission, 2006 www.ada.gov/qandaeng.htm
- 2005 Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities—People's Piece http://www.surgeongeneral.gov/library/disabilities/calltoaction/whatitmeanstoyou.pdf

Back:

- AAHD Brochures
- Information on Disability and Health Journal of AAHD
- Educational Materials from D.C. Metro Area Susan G. Komen for the Cure® Grantees