



Published in final edited form as:

*Intellect Dev Disabil.* 2019 June ; 57(3): 177–187. doi:10.1352/1934-9556-57.3.177.

## Racial/Ethnic Disparities in Mammogram Frequency Among Women With Intellectual Disability

**Evelyn Arana**

Cancer Disparities Center, Hackensack University Medical Center;

**Amy Carroll-Scott, Philip M. Massey, Nora L. Lee, Ann C. Klassen, Michael Yudell**

Drexel University Dornsife School of Public Health.

### Abstract

Little information exists on the associations between intellectual disability (ID) and race/ethnicity on mammogram frequency. This study collected survey and medical record data to examine this relationship. Results indicated that Hispanic and Black women with ID were more likely than White women with ID to have mammograms every 2 years. Participants who live in a state-funded residence, were aged 50+, and had a mild or moderate level of ID impairment were more likely to undergo mammography compared to participants living with family or alone, were <50, and had severe ID impairment. Further research is needed to understand the mechanisms explaining disparities in mammograms between these racial/ethnic groups.

### Abstract

Il existe peu d'informations sur les associations entre la déficience intellectuelle (DI) et la race ou l'ethnie sur la fréquence des mammographies. Cette étude a rassemblé des données d'enquêtes et de dossiers médicaux pour examiner cette relation. Les résultats ont indiqué que les femmes hispaniques et noires ayant une DI étaient plus susceptibles que les femmes blanches ayant une DI de passer une mammographie tous les 2 ans. Les participantes qui vivaient dans une résidence financée par l'État, qui étaient âgées de 50 ans et plus et qui présentaient une DI légère ou modérée, étaient plus susceptibles de passer une mammographie que les participantes qui vivaient seules ou avec leur famille, qui avaient moins de 50 ans et qui présentaient une DI sévère. Des recherches supplémentaires sont nécessaires pour comprendre les mécanismes expliquant les disparités dans la passation de mammographies entre ces groupes raciaux ou ethniques.

### Abstract

Existe poca información sobre las asociaciones entre la discapacidad intelectual (DI) y la raza / etnia sobre la frecuencia de las mamografías. Este estudio recopiló datos de encuestas y registros médicos para examinar esta relación. Los resultados indicaron que las mujeres hispanas y africanas con identificación eran más propensas que las mujeres blancas con identificación a realizarse mamografías cada 2 años. Los participantes que viven en una residencia financiada por el estado, tenían más de 50 años y tenían un nivel leve o moderado de discapacidad intelectual,

eran más propensos a someterse a una mamografía en comparación con los participantes que vivían con familia o solos, tenían menos de 50 años y tenían un diagnóstico de discapacidad intelectual grave. Se necesita más investigación para comprender los mecanismos que explican las disparidades en las mamografías entre estos grupos raciales / étnicos.

### Keywords

intellectual disability; breast cancer; health disparities

---

### Background

Approximately 8 million people live with intellectual disability (ID) in the United States, or 3% of the population (Administration for Community Living, 2016). ID is characterized by significant limitations in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills (American Association on Intellectual and Developmental Disabilities, 2013). People with ID continue to face significant health disparities, including access to primary care and psychiatric care (Jensen, Taylor, & Davis, 2013; Ouellette-Kuntz et al., 2005). Disparities in mammography for women with ID also exist but have received limited attention. Research on the rates of breast cancer for women with ID has been mixed, with one study reporting similar rates to women without disabilities (Patja, Eero, & Iivanainen, 2001) and other studies reporting reduced rates (Davies & Duff, 2001; Wilkinson, Lauer, Freund, & Rosen, 2011), suggesting possible screening disparities. One study found that women with ID are more likely to be diagnosed with late stages of breast cancer (Sátgé et al., 2014).

Mammography is an evidence-based screening test that identifies breast cancer at earlier stages and, when combined with effective treatment, reduces morbidity and mortality from breast cancer (Humphrey, Helfand, Chan, & Woolf, 2002). Two prominent medical groups currently offer differing mammogram guidelines. The United States Preventive Services Task Force (USPSTF; 2016) recommends biennial screening mammography for women ages 50–74 years of age, and the American Cancer Society (ACS; 2017) recommends annual screening mammography for women ages 40 and up and continuing for as long as the woman is in good health. The Centers for Disease Control and Prevention (CDC) reports that 72.5% of women in the general population ages 40 and older had a mammogram in the past 2 years (2017).

Prior disparities in mammograms in the U.S. general population among Black and White women (McCarthy et al., 1998; Ward et al., 2004) appear to have been reduced significantly in recent years, with Black women's biennial mammogram rates nationally now higher than White women's rates (72.3% vs 68.2%; National Center for Health Statistics, 2017). However, disparities in breast cancer morbidity and mortality persist (Peek & Jini, 2004; Tian, Goovaerts, Zhan, & Wilson, 2010). Although White women have higher breast cancer incidence rates than Black women, Black women have a higher mortality rate of breast cancer (Kaklamani et al., 2013; Siegel, Ma, Zou, & Jemal, 2014). A 2014 study that looked at national mammogram utilization rates of Hispanic women in the Avon Breast Health

Outreach Program found that only 41.1% of Hispanic women reported a mammogram in the last 2 years (Gates-Ferris, Senter, Aliaga, Hurlbert, Ricci, 2015).

Few studies have explored mammogram disparities among women with ID. In a study that conducted postal surveys of women with ID with a response rate of 59%, only 46% reported having a mammogram in the past 3 years (Davies & Duff, 2001). Secondary data analysis of the Massachusetts Department of Developmental Services database found that only 53% of women with ID had a mammogram in the past 2 years (Wilkinson et al., 2011), suggesting women with ID have lower mammogram rates than the 72.5% rate from the general population. Kirby and Hegarty (2010) found that 72% of nurses within ID settings do not promote breast awareness for women with ID.

Two studies have examined racial/ethnic disparities in mammography among women with ID. In a study that analyzed a combined dataset from the 2009–2010 and 2010–2011 National Core Indicators—a performance measurement system that collects data on over 20,000 participants receiving ID services from 40 states—Scott and Havercamp (2014) found that Black women were more likely to have a mammogram in the past 2 years (62%) as compared to White (50%) and Hispanic (30%) women. This is in contrast to findings by Parish, Swaine, Son, and Luken (2013), in which medical record data determined that White women with ID were three times more likely to undergo mammography in the past 2 years compared to Black women with ID.

In sum, available evidence indicates women with ID are less likely to have a mammogram every 2 years than the general population. Further, there are mixed findings from the limited research on racial/ethnic disparities among women with ID. Additional research is needed to understand the extent of these disparities.

Intersectionality theory posits that individuals' lives are not affected by a single identity, but rather that multiple social identities interlock to reflect systems of privilege and oppression (Crenshaw, 1991). Women with ID are, at baseline, already faced with oppressed identities—having ID and being a woman. Women with ID who are of a minority racial/ethnic group face an additional disadvantage, thus bestowing upon them multiple disadvantages that may worsen their health compared to White women with ID and to the general population. The purpose of this study was, thus, to collect survey and electronic health record data from women with ID to explore racial/ethnic disparities in mammogram frequency. Gaining a better understanding of these disparities may help facilitate screening promotion and health care access efforts.

## Methods

### Sampling and Recruitment

Participants were recruited using nonprobabilistic purposive sampling from ID settings such as adult day programs, support coordinator organizations, and residential facilities across Philadelphia, PA. These organizations were contacted by email and phone and presentations were given to facilitate discussion of the study with support coordinators, program managers, families, and potential participants and their caregivers. Organizations

that were interested and available to help with recruitment identified women with ID from their organization who may have been eligible to participate. Contact information was only released to the researcher if the women with ID or her caregiver agreed to be contacted.

### Participant Eligibility

Eligible participants were females who were at least 40 years old in 2010; had a clinical diagnosis of intellectual disability; had no personal or first-degree family history of breast cancer; were residents of Philadelphia; self-identified as White, Hispanic, or Black; and were English or Spanish speakers.

### Consent Procedures

It was important in this study to determine whether a participant had the cognitive capacity to provide consent. After reviewing the consent form, all participants were asked the following:

1. Why are we doing this project?
2. What would you have to do if you decided to be in this project?
3. Do you have to do this project?
4. What are the benefits of this project?
5. What are the risks of this project?
6. When can you choose to stop being in the project?

If all questions were answered correctly, the participant was deemed capable of providing consent. If a participant answered at least one question incorrectly, consent was obtained from their caregiver. If there was no caregiver available and the participant answered at least one question wrong, the participant was not enrolled in the study. All enrolled participants also filled out a Health Insurance Portability and Accountability Act of 1996 (HIPAA) medical release form that granted permission for the participant's health care provider to release medical record data about the participant.

### Data Collection

Women who enrolled in the study participated in one interviewer-administered survey that included questions on the participant's marital status, living arrangement, and health insurance status. All surveys were administered at the home of the participant or at the organization through which they were recruited. Age, zip code, and race/ethnicity data were collected from the eligibility screening form in person or via phone prior to consent procedures. Mammogram dates from 2010–2013 and ID impairment severity were collected from the participant's health care provider with the participant's signed HIPAA form. Participants were paid \$15 for their time. The Drexel University Institutional Review Board approved the study protocol.

## Measures

**Dependent variable.**—Mammogram frequency was the dependent variable, categorized as insufficiently screened, biennially, and annually. “Insufficiently screened” included participants who had never received a mammogram in the past or had 0 to 1 mammogram in the 4-year period of data that ranged from 2010–2013. “Biennially” included participants who had 2 or 3 mammograms from 2010–2013, corresponding to participants who met the USPSTF guidelines that recommend women ages 50–74 receive a mammogram every 2 years (United States Preventive Task Force, 2016), but did not receive mammograms in each of the 4 years of data collection. “Annually” referred to participants who had a mammogram each year from 2010–2013, corresponding to participants who met the ACS guidelines that recommend women ages 40 and over have annual mammograms (American Cancer Society, 2017).

**Independent variable.**—Race/ethnicity, coded as White (non-Hispanic), Black (non-Hispanic), and Hispanic, served as the focal independent variable of the study.

**Covariates.**—Age was dichotomized as 40–49 and 50–70. Living arrangement was categorized as family or alone, Intermediate Care Facility (ICF), and Community Living Arrangement (CLA). ICFs are supported by federal and state funds and are specifically designed to furnish health and rehabilitative services to people with intellectual disability (Pennsylvania Department of Human Services, 2018). CLAs are private homes in which two to three individuals with intellectual disability reside together and are provided with opportunities for increased independence and community participation (Pennsylvania Department of Health, 2015). ID impairment severity level was categorized as mild, moderate, and severe.

Zip code of residence was used as a proxy for neighborhood socioeconomic status (NES) and was categorized according to the percentage of households in the zip code that fall below the federal poverty level (FPL) guidelines (U.S. Department of Health and Human Services, 2017), drawn from the U.S. Census Bureau’s 2015 American Community Survey (U.S. Census Bureau, 2015). Categories included 0–20% of households below FPL, 20–30% of households below FPL, and over 30% of households below FPL. Studies measuring the association between neighborhood socioeconomic status on various health outcomes have often used zip codes to represent neighborhoods (McCarthy, Dumanovsky, Visvanathan, Kahn, & Schymura, 2010; Rundle et al., 2009). Verbal ability was dichotomized as verbal or nonverbal, language was dichotomized as English or Spanish, and consenting person was dichotomized as self or proxy. Health insurance and marital status were also collected, but not included in analyses because all participants were insured and unmarried.

## Analytic Methods

Unadjusted associations between the dependent variable and covariates were explored using Pearson’s chi-squared test or Fisher’s exact probability test. The latter was used in instances of one or more of the cells having an expected frequency of five or less (Agresti & Finlay, 1986). An adjusted multinomial logistic regression model was estimated in which age, living arrangement, NES, and ID impairment severity were held constant to test for associations

between mammogram frequency and race/ethnicity. “Insufficiently screened” and “White” were the referent groups for the dependent and focal independent variables, respectively. Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated. Goodness-of-fit tests, model fitting information, and pseudo  $R^2$  confirmed that each model was a good fit. Data were analyzed using the Statistical Package for Social Sciences (SPSS; version 24).

## Results

Characteristics of the 95 participants with intellectual disability who consented to enroll in the study are shown in Table 1. Over half of the sample (74.4%) demonstrated capacity to give consent and were verbal (72.6%). The sample was comprised of 34 White participants (35.8%), 43 Black (45.3%), and 18 Hispanic (18.9%) women with ID. Most participants spoke English (87.4%), and all participants who spoke Spanish were Hispanic. Participants ranged in age from 40 to 70 and just over half were 50 years or older (51.6%). Almost half of participants lived in CLAs; only 15.8% lived in ICFs. Slightly less than half of participants had a mild level of ID impairment (45.3%), 26.3% had a moderate level of ID impairment, and 28.4% had a severe level of ID impairment. The majority of participants lived in neighborhoods where 0–20% of households fell below the FPL (60.0%), or at the upper end of the poverty spectrum as defined by FPL. Mammogram records were provided for all participants by their health care provider. Forty-three percent of participants had a mammogram annually and one-third received one biennially (33.7%).

Chi-squared tests in Table 1 show that age, ID severity, verbal ability, consenting person, and mammogram frequency were similar across all racial/ethnic groups. NES ( $p = 0.03$ ), living arrangement ( $p = 0.01$ ), and language ( $p = 0.000$ ) differed significantly across racial/ethnic groups. Additional chi-square tests also showed that Hispanic participants were significantly more likely to live in poorer neighborhoods than White and Black participants. There were no significant differences in NES between White and Black participants (data not shown). Verbal ability, language, and consenting person were similar in mammogram frequency (data not shown).

Table 1 also presents mammogram frequencies from 2010–2013. Just under a quarter of this sample were insufficiently screened (23.2%), just under half had a mammogram annually (43.2%), and a third had a mammogram biennially (33.7%). Bivariate analyses of racial/ethnic differences demonstrate that, during this time, more White women with ID were insufficiently screened (32.4%) than Black (18.6%) and Hispanic (16.7%) women. More Black women in our sample were screened biennially (44.2%) compared to Hispanic (38.9%) and White (17.7%) women with ID. However, more White women were annually screened (50.0%), followed by Hispanic (44.4%) and Black (37.2%) women.

Table 2 regression results demonstrate that Black (OR = 5.5; 95% CI, 1.0–28.0) and Hispanic (OR = 9.5, 95% CI, 1.0–91.9) women with ID were more likely than White women with ID to be screened biennially, even after controlling for age, living arrangement, ID impairment severity, and NES. Black and Hispanic participants were less likely than White participants to be screened annually, although this was not significant. Participants living in CLAs were significantly more likely than participants living with family/alone to be



screened biennially (OR = 5.69; 95% CI, 0.8–38.2) and annually (OR = 11.3; 95% CI, 1.78–71.8). There were no significant differences in screening when comparing participants living in ICFs and with family or alone. When looking at these state-funded residences combined, in addition to predicting higher mammogram rates, state residences also predict an annual mammogram schedule, with 65.4% vs. 34.6% of state residences predicting annual over biennial mammography, respectively, although this finding was not significant (data not shown).

Participants who were 50 years or older were more likely than participants ages 40–49 to be screened annually (OR = 6.3; CI, 1.5–27.7). Compared to participants with severe levels of ID impairment, participants with mild and moderate levels of ID impairment were more likely to be screened biennially (Mild: OR = 19.8; 95% CI, 2.6–148.1; Moderate: OR = 13.8, 95% CI, 1.6–119.7) and annually (Mild: OR = 1.3, 95% CI, 1.3–64.9; Moderate: OR = 16.5; 95% CI, 2.0–133.6).

## Discussion

This study contributes to the nascent literature examining disparities in mammogram frequency across racial/ethnic groups of women with intellectual disability. Results show that after controlling for age, neighborhood socioeconomic status, living arrangement, and level of ID impairment severity, Black and Hispanic women with ID were significantly more likely to have mammograms biennially than White women with ID. This corroborates a previous study that found Black women with ID were more likely to receive a mammogram in the past 2 years than White women with ID (Scott & Havercamp, 2014). Nationally, among women without ID, Black women have higher rates of receiving a mammogram in the past 2 years, while Hispanic women have lower rates of receiving a mammogram in the past 2 years compared to White women (Centers for Disease Control and Prevention [CDC], 2017). It is also important to highlight that, in this study, White women had the highest percentage of receiving annual mammograms and also had the highest percentage of being insufficiently screened compared to Black and Hispanic women with ID—although these differences were not significant. White women having a higher percentage of being insufficiently screened may be attributable to their residential status (living with family or alone) and also to the severe level of impairment that several of them living in ICFs have. The latter finding of White women receiving the highest percentage of annual mammograms was not seen within the subsample of women receiving state residential services, yet it remained among the subgroup of women with ID living with family or alone. Research notes that socioeconomic position and race/ethnicity affect healthcare access. Racial minorities are less likely to afford health care (Potosky, Breen, Graubard, & Parsons, 1998), have transportation (Heckman et al., 1998), or have access to education (Pincus, Esther, DeWalt, & Callahan, 1998), and more likely to experience provider bias (van Ryn & Burke, 2000). Black and Hispanic participants living with family may be experiencing more barriers to mammography than White participants, which may be leading Black and Hispanic participants to screen less often than White participants. Additional research is needed to determine why these disparities exist among women with ID.

The majority of women in this study were found to be receiving timely mammography. This study shows biennial mammogram rates for women with ID at 33.7% and annual rates at 43.2%. Thus, 76% of participants in our sample receive mammograms every 1 or 2 years. This rate is higher than the Behavior Risk Factor Surveillance System (BRFSS) national rates of 72.5% for the general population (CDC, 2017) and goes against other research that found that women with ID have significantly lower rates of mammograms than the general population (National Core Indicators, 2015; Wilkinson et al., 2011). Participants may be experiencing less barriers to mammography, including more support from either a family or provider and may have a primary care provider that supports and reminds these women to have a mammogram. It may be that women with ID in this study differ significantly from those women with ID not in this study.

After examining key study associations between race/ethnicity and mammogram frequency, several additional characteristics were associated with increased mammogram frequency. Participants living in a community living arrangement had a higher likelihood of undergoing biennial and annual mammography than participants living with family or alone, whereas participants living in an intermediate care facility did not significantly differ in likelihood of being screened than those that live with family or alone. This former finding corroborates previous research on the positive effect of residential setting on mammogram receipt among women with ID (Wilkinson et al., 2011). Those living in state-funded residences are afforded care coordination benefits such as support coordinators or nurses, who may be effectively assisting these women in scheduling and attending mammogram appointments (Bershadsky, Sarah, & Joshua, 2012). Indeed, the positive association of care coordination and mammography has been documented (Balogh, Ouellette-Kuntz, Bourne, Lunsky, & Colantonio, 2008; Wilkinson et al., 2011). State-funded residence may also predict an annual over a biennial mammogram schedule, although this finding was not significant. Moreover, ICFs and CLAs have funding regulations that protect the health, safety, and well-being of individuals with intellectual disability. Regulations that monitor ICFs and CLAs both require that women receive a mammogram at least every 2 years for women 40–49 years of age and at least every year for women 50 years of age and older. However, in this study, most participants in ICFs had severe levels of ID, which may have impeded their completion of a mammogram. This may help explain why participants living in ICFs did not have a higher likelihood of screening than those living with family or alone. Women with ID living with family caregivers or alone may be less able to consistently access or navigate preventive care than those living in a state-funded residence. Wilkinson et al. (2011) suggest the need for piloting interventions drawing from the patient-centered medical home movement that would address these preventive care needs and coordination for women with ID not living in state-funded residences.

Women with mild or moderate levels of ID were also more likely to be screened biennially and annually than women with a severe level of ID impairment. Previous research has found that women with mild or moderate levels of ID were more likely to have some knowledge of mammograms (Parish, Swaine, Luken, Rose, & Dababnah, 2012). In addition, women with severe levels of ID impairment may be less cooperative or physically incapable of undergoing mammography (Diab & Johnston, 2004). It is important to note that all participants with severe levels of ID impairment screened annually in this study lived in



state-funded residential homes. It is likely that, as noted by Parish et al. (2013), during care coordination, a nurse reminds the health care provider to consider a mammogram and then ensures procedures are in place (e.g., sedation is adequately administered). More research is needed to determine barriers to mammogram rates for women with severe levels of ID impairment.

Women with ID who were 50–70 years of age were also more likely to be screened annually than women with ID who were 40–49 years of age. It may be that health care providers are not recommending mammograms until the woman with ID is 50 years of age. This could be due to several factors: the women with ID have other health concerns that take priority; the families do not feel comfortable with mammography; or health care providers may have preconceived notions about women with ID, such as believing people with ID are asexual (Esmail, Darry, Walter, Knupp, 2010; Greenwood, Dreyfus, & Wilkinson, 2014; Wilkinson & Cerreto, 2008). The health care provider and participant may have also decided to follow the USPSTF mammogram clinical guidelines, which recommends mammograms beginning at age 50. Insurance coverage of breast cancer screening was likely not an issue with this sample, as all women in this study have health insurance.

### Limitations and Strengths

This study has several limitations that should be considered when interpreting the findings. Extensive outreach was conducted through organizations serving women with ID in Philadelphia to recruit a racially diverse sample of women with ID that was balanced between the racial/ethnic categories of focus for this study: White, Black, and Hispanic. Recruitment challenges included finding and accessing women with ID, particularly those living with families and not regularly accessing services from ID organizations, and Hispanic women with ID who are a smaller population than White and Black women with ID in Philadelphia, and are likely a more “hidden” population from city ID organizations. Nevertheless, the women and families spoken to in this study were highly likely to consent due to the extensive outreach and trust-building created with ID organizations in Philadelphia. The lack of balance between racial/ethnic categories limited power for examining racial/ethnic differences in mammogram frequency and, thus, results may not be generalizable to the general population of women with ID. The wide confidence interval reflects this study’s small sample size and, thus, caution should be made in interpreting findings. Given the small sizes of each of the racial/ethnic categories, differences between groups should be confirmed in larger studies. Although mammography history forms were completed and returned by health care providers for all participants, it is possible that home-dwelling women might be more likely to receive mammograms from multiple sources without their health care provider’s knowledge, and that this difference could account for some of the differences by residence.

All women in this study were registered with the Philadelphia Disability Service System and receive residential, vocational, educational, and/or case management services. Investigating the extent of racial/ethnic disparities in mammography for women who were not registered with the service system was beyond the scope of this study, but could further identify groups at risk for screening disparities.

Despite these limitations, this study has important strengths. Our sample mirrored national data of adults with ID on several characteristics, including living situation and ID impairment. In this study, 62.1% of participants lived in state-funded residential settings, similar to the national rate of 50% of adults who live in state-funded residential settings and represent women with ID across the disability spectrum (National Core Indicators, 2015). Thus, our data are most generalizable to women with ID living in state-funded residences, but do represent women with ID across the impairment spectrum.

Furthermore, mammogram data was collected directly from medical records, eliminating social desirability bias or recall bias. Second, women were recruited from a wide geographic area comprised of 34 different zip codes across Philadelphia.

### Implications & Future Research

This study shows some evidence of racial/ethnic differences in mammography among women with ID. This warrants additional exploration.

Although mammogram rates for this population are higher than national rates, it is vital that efforts to continue to increase their mammogram rates continue. Providers who work with people with ID are in unique positions to advocate for women with ID to undergo mammography. Discussions on mammograms and breast cancer should be included as part of an individual support plan and required as part of the annual service planning meetings. It is also important for providers to incorporate other modes of communication, such as using images, with women with ID who may have poor receptive and expressive language. Research shows that women with disabilities fear mammography procedures (Tezzoni, McCarthy, Davis, Harris-David, & O'Day, 2001). Service plans have the potential to help women with ID learn more about mammography and may reduce fear of the exam.

Health care professionals should encourage and recommend mammography for women with ID. But health care professionals may lack appropriate training in working with individuals with ID and, thus, may not recommend preventive health exams (Greenwood et al., 2014; Wilkinson & Cerreto, 2008). There are currently no formal trainings for mammogram staff in working with women with ID. However, the American Association on Health & Disability has created a factsheet for mammography staff on how to serve women with disabilities more effectively (AAHD; 2009). There are also promising efforts underway that could improve mammograms among women with ID, such as training medical students and residents on the health care concerns of people with ID and engaging people with ID to help students and residents communicate more effectively with other people with ID (Thomas, Courtenay, Hassiotis, Strydom, & Rantell, 2014). This has shown significant improvements in communication skills and quality of care provided to the person with ID.

Exploring mammogram disparities for women with ID who live with family or alone is an important direction for future research. It is possible that participants screened annually and biennially have a stronger supportive network that includes care coordination support and family support. Future research should explore these factors in relation to mammography. Additional research with a larger sample size is needed to further study racial/ethnic disparities in mammography among women with ID. A longitudinal study that follows

a cohort of women with ID to understand predictors of breast cancer incidence is also warranted.

## Acknowledgments

This project was supported by grant number R36HS023966 from the Agency for Healthcare Research and Quality (AHRQ) Health Services Dissertation Grant. The Drexel University Institutional Review Board approved the study protocol. Dr. Arana would like to give special thanks to Patricia Graves, Director of Nursing at the Philadelphia Coordinated Health Care, for her help in identifying organizations in Philadelphia that serve individuals with intellectual disability. This research was conducted while Dr. Arana was a DrPH Candidate at the Dornsife School of Public Health at Drexel University.

## References

- Administration for Community Living. (2016). The President's Committee for People with Intellectual Disabilities. Retrieved from <https://acl.gov/programs/empowering-advocacy/presidents-committee-people>
- Agresti A, & Finlay B (1986). Statistical methods for the social sciences. San Francisco, CA: Dellen Publishing Company and London, England: Collier Macmillan Publishers.
- American Association on Health & Disability. (2009). Tips for mammography staff: How to serve women with disabilities more effectively. Retrieved from <http://www.aahd.us/wp-content/uploads/2012/03/MammoTipsStaff2009.pdf>
- American Association on Intellectual and Developmental Disabilities. (2013). Frequently asked questions on intellectual disability. Retrieved from <https://aaid.org/intellectual-disability/definition/faqs-on-intellectual-disability#.Vwa5txMrLp4>
- American Cancer Society. (2017). American Cancer Society guidelines for early detection of cancer. Retrieved from <http://www.cancer.org/healthy/findcancerearly/cancerscreeningguidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer>
- Balogh R, Ouellette-Kuntz H, Bourne L, Lunsy Y, & Colantonio A (2008). Organising health care services for persons with an intellectual disability. *Cochrane Database of Systemic Reviews*, 4. 10.1002/14651858.CD007492
- Bershady J, Sarah T, & Joshua E (2012). Place of residence and preventive health care for intellectual and developmental disabilities services recipients in 20 states. *Public Health Reports*, 127(5), 475–485. 10.1177/003335491212700503 [PubMed: 22942465]
- Centers for Disease Control and Prevention. (2017). BRFSS prevalence & trends data. Retrieved from <https://www.cdc.gov/brfss/brfssprevalence/>
- Crenshaw K (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*. 43(6), 1241–1299. 10.2307/1229039
- Davies N, & Duff M (2001). Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research* 45(3), 253–257. 10.1046/j.1365-2788.2001.00313.x [PubMed: 11422650]
- Diab ME, & Johnston MV (2004). Relationships between level of disability and receipt of preventive health services. *Archives of Physical Medicine and Rehabilitation*. 85(5), 749–757. [PubMed: 15129399]
- Esmail S, Darry K, Walter A, & Knupp H (2010). Attitudes and perceptions towards disability and sexuality. *Journal of Disability and Rehabilitation*. 32(14), 1148–1155. 10.3109/09638280903419277 [PubMed: 20131952]
- Gates-Ferris K, Senter L, Aliaga M, Hurlbert M, & Ricci C (2015). The effect of Hispanic nativity and ethnicity on mammography use through the Avon breast health outreach program [Abstract P1–09–06]. Retrieved from [http://cancerres.aacrjournals.org/content/76/4\\_Supplement/P1-09-06.short](http://cancerres.aacrjournals.org/content/76/4_Supplement/P1-09-06.short)
- Greenwood NW, Dreyfus D, & Wilkinson J (2014). More than just a mammogram: Breast cancer screening perspectives of relatives of women with intellectual disability. *Intellectual and Developmental Disabilities*, 52(6), 444–455. 10.1352/1934-9556-52.6.444 [PubMed: 25409131]

- Heckman TG, Somial AM, Peters J, Walker J, Otto-Salaj L, Galdabini CA, & Kelly JA (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*, 10(3), 365–375. 10.1080/713612410 [PubMed: 9828979]
- Humphrey LL, Helfand M, Chan BK, & Woolf SH (2002). Breast cancer screening: a summary of the evidence for the US Preventive Services Task Force. *Annals of internal medicine*, 137(5\_Part\_1), 347–360. 10.7326/0003-4819-137-5\_Part\_1-200209030-00012 [PubMed: 12204020]
- Jensen KM, Taylor LC, & Davis MM (2013). Primary care for adults with Down syndrome: adherence to preventive healthcare recommendations. *Journal of Intellectual Disability Research*, 57(5), 409–421. 10.1111/j.1365-2788.2012.01545.x [PubMed: 22463763]
- Kaklamani VG, Hoffman JT, Thornton AT, Hayes G, Chlebowski R, Van Horn L, & Mantzoros C (2013). Adiponectin pathway polymorphisms and risk of breast cancer in African Americans and Hispanics in the Women’s Health Initiative. *Breast Cancer Research and Treatment*, 139(2), 461–468. [PubMed: 23624817]
- Kirby S, & Hegarty J (2010). Breast awareness within an intellectual disability setting. *European Journal of Oncology Nursing*, 14(4), 328–336. 10.1016/j.ejon.2010.03.005 [PubMed: 20493767]
- McCarthy AM, Dumanovsky T, Visvanathan K, Kahn AR, & Schymura MJ (2010). Racial/ethnic and socioeconomic disparities in mortality among women diagnosed with cervical cancer in New York City, 1995–2006. *Cancer Causes Control*, 21(10), 1645–1655. 10.1007/s10552-010-9593-7 [PubMed: 20521091]
- McCarthy EP, Burns RB, Coughlin SS, Freund KM, Rice J, Marwill SL, ... Moskowitz MA (1998). Mammography use helps to explain differences in breast cancer diagnosis between older Black and White women. *Annals of Internal Medicine*, 128(9), 729–736. 10.7326/0003-4819-128-9-199805010-00005 [PubMed: 9556466]
- National Center for Health Statistics. (2017). *Health, United States, 2016: With chartbook on long-term trends in health*. Hyattsville, MD: Author
- National Core Indicators. (2015). Chart Generator 2014–15. Retrieved from <http://www.nationalcoreindicators.org/charts/>
- Ouellette-Kuntz H, Garcin N, Lewis MS, Minnes P, Martin C, & Holden JJ (2005). Addressing health disparities through promoting equity for individuals with intellectual disability. *Canadian Journal of Public Health*, S8–S22.
- Parish SL, Swaine JG, Luken K, Rose RA, & Dababnah S (2012). Cervical and breast cancer-screening knowledge of women with developmental disabilities. *Intellectual and Developmental Disabilities*, 50(2), 79–91. 10.1352/1934-9556-50.2.79 [PubMed: 22642963]
- Parish SL, Swaine JG, Son E, Luken K (2013). Receipt of mammography among women with intellectual disabilities: medical record data indicate substantial disparities for African American women. *Disability and Health Journal*. 6(1), 36–42. 10.1016/j.dhjo.2012.08.004 [PubMed: 23260609]
- Patja K, Eero P, & Iivanainen M (2001). Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research*, 45(4), 300–307. 10.1046/j.1365-2788.2001.00322.x [PubMed: 11489051]
- Peek ME, & Jini HH (2004). Disparities in screening mammography. *Journal of General Internal Medicine*, 19(2), 184–194. 10.1111/j.1525-1497.2004.30254.x [PubMed: 15009798]
- Pennsylvania Department of Health. (2015). Philadelphia resource guide. Retrieved from <http://www.health.pa.gov/My%20Health/Documents/Philadelphia%20County%20Resource%20Guide.pdf>
- Pennsylvania Department of Human Services. (2018). Intermediate care facilities. Retrieved from <http://www.dhs.pa.gov/citizens/intellectualdisabilitiesservices/intermediatecarefacilities/index.htm>
- Pincus T, Esther R, DeWalt DA, & Callahan LF (1998). Social conditions and self-management are more powerful determinants of health than access to care. *Annals of Internal Medicine*, 129(5), 406–411. 10.7326/0003-4819-129-5-199809010-00011 [PubMed: 9735069]
- Potosky AL, Breen N, Graubard BI, & Parsons PE (1998). The association between health care coverage and the use of cancer screening tests. *Medical Care*, 36(3), 257–270. 10.1097/00005650-199803000-00004 [PubMed: 9520952]

- Rundle A, Neckerman KM, Freeman L, Lovasi GS, Purciel M, Quinn J, ... Weiss C (2009). Neighborhood food environment and walkability predict obesity in New York City. *Environmental Health Perspectives*, 117(3), 442–447. 10.1289/ehp.11590 [PubMed: 19337520]
- Satgé D, Sauleau EA, Jacot W, Raffi F, Azéma B, Bouyat JC, & Assaf NEH (2014). Age and stage at diagnosis: A hospital series of 11 women with intellectual disability and breast carcinoma. *BMC Cancer*, 14(1), 1–6. 10.1186/1471-2407-14-150 [PubMed: 24383403]
- Scott HM, & Havercamp SM (2014). Race and health disparities in adults with intellectual and developmental disabilities living in the United States. *Intellectual and Developmental Disabilities*, 52(6), 409–418. 10.1352/1934-9556-52.6.409 [PubMed: 25409129]
- Siegel R, Ma J, Zou Z, & Jemal A (2014). Cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, 64(1), 9–29. 10.3322/caac.21208 [PubMed: 24399786]
- Tezzoni LI, McCarthy EP, Davis RB, Harris-David L, & O'day B (2001). Use of screening and preventive services among women with disabilities. *American Journal of Medical Quality*, 16(4), 135–144. 10.1177/106286060101600405 [PubMed: 11477958]
- Thomas B, Courtenay K, Hassiotis A, Strydom A, & Rantell K (2014). Standardised patients with intellectual disabilities in training tomorrow's doctors. *Psychiatric Bulletin*, 38(3), 132–136. 10.1192/pb.bp.113.043547
- Tian N, Goovaerts P, Zhan FB, & Wilson GJ (2010). Identification of racial disparities in breast cancer mortality: does scale matter? *International Journal of Health Geographics*, 9(1), 1–14. 10.1186/1476-072X-9-35 [PubMed: 20082711]
- United States Preventive Services Task Force. (2016). Breast cancer: Screening. Retrieved from <http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/breast-cancer-screening>
- U.S. Census Bureau. (2015). Disability characteristics. 2011–2015 American Community Survey 5-Year estimates Retrieved from [https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_15\\_5YR\\_S1810&prodType=table](https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_15_5YR_S1810&prodType=table).
- U.S. Department of Health and Human Services. (2015). The HIPAA Privacy Rule. Retrieved from <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>.
- U.S. Department of Health and Human Services. (2017). U.S. federal poverty guidelines used to determine financial eligibility for certain federal programs Retrieved from <https://aspe.hhs.gov/poverty-guidelines>
- van Ryn M, & Burke J (2000). The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science & Medicine*, 50(6), 813–828. 10.1016/S0277-9536(99)00338-X [PubMed: 10695979]
- Ward E, Jemal A, Cokkinides V, Singh GK, Cardinez C, Ghafoor A, & Thun M (2004). Cancer Disparities by Race/Ethnicity and Socioeconomic Status. *CA: A Cancer Journal for Clinicians*, 54(2), 78–93. 10.3322/canjclin.54.2.78 [PubMed: 15061598]
- Wilkinson JE, & Cerreto MC (2008). Primary care for women with intellectual disabilities. *The Journal of the American Board of Family Medicine*, 21(3), 215–222. 10.3122/jabfm.2008.03.070197 [PubMed: 18467533]
- Wilkinson JE, Lauer E, Freund MK, & Rosen KA (2011). Determinants of mammography in women with intellectual disabilities. *The Journal of the American Board of Family Medicine*, 24(6), 693–703. 10.3122/jabfm.2011.06.110095 [PubMed: 22086812]

**Table 1**

Description of Sample, *n* = 95, Philadelphia, PA

| Characteristic                    | White <i>n</i> (%) | Hispanic <i>n</i> (%) | Black <i>n</i> (%) | Total <i>n</i> (%) | <i>p</i> -value |
|-----------------------------------|--------------------|-----------------------|--------------------|--------------------|-----------------|
| Age                               |                    |                       |                    |                    |                 |
| 40–49                             | 20 (58.8%)         | 11 (61.1%)            | 28 (65.1%)         | 46 (48.4%)         | 0.06            |
| 50–70                             | 14 (41.2%)         | 7 (38.9%)             | 15 (34.9%)         | 49 (51.6%)         |                 |
| Living Arrangement                |                    |                       |                    |                    |                 |
| Family or alone                   | 10 (29.4%)         | 5 (27.8%)             | 21 (48.8%)         | 36 (37.9%)         | 0.01*           |
| Intermediate Care Facility        | 11 (32.4%)         | 2 (11.1%)             | 2 (4.7%)           | 15 (15.8%)         |                 |
| Community Living Arrangement      | 13 (38.2%)         | 11 (61.1%)            | 20 (46.5%)         | 44 (46.3%)         |                 |
| ID Impairment Level               |                    |                       |                    |                    |                 |
| Mild                              | 10 (29.4%)         | 9 (50.0%)             | 24 (55.9%)         | 43 (45.3%)         | 0.08            |
| Moderate                          | 9 (26.5%)          | 4 (22.2%)             | 12 (27.9%)         | 25 (26.3%)         |                 |
| Severe                            | 15 (44.1%)         | 5 (27.8%)             | 7 (16.3%)          | 27 (28.4%)         |                 |
| Neighborhood Socioeconomic Status |                    |                       |                    |                    |                 |
| 0–20% households below FPL        | 23 (67.7%)         | 11 (61.1%)            | 23 (53.5%)         | 57 (60.0%)         | 0.03*           |
| 20–30% households below FPL       | 9 (26.5%)          | 1 (5.6%)              | 14 (32.6%)         | 24 (25.3%)         |                 |
| 30+ % households below FPL        | 2 (5.9%)           | 6 (33.3%)             | 6 (13.9%)          | 14 (14.7%)         |                 |
| Verbal Ability                    |                    |                       |                    |                    |                 |
| Verbal                            | 22 (64.7%)         | 13 (72.2%)            | 34 (79.1%)         | 69 (72.6%)         | 0.373           |
| Nonverbal                         | 12 (35.3%)         | 5 (27.8%)             | 9 (20.9%)          | 26 (27.4%)         |                 |
| Consenting Person                 |                    |                       |                    |                    |                 |
| Self                              | 19 (55.9%)         | 11 (61.1%)            | 43 (74.4%)         | 32 (74.4%)         | 0.218           |
| Proxy                             | 15 (44.1%)         | 7 (38.9%)             | 11 (25.6%)         | 11 (25.6%)         |                 |
| Language                          |                    |                       |                    |                    |                 |
| English                           | 34 (100%)          | 6 (33.3%)             | 43 (100%)          | 83 (87.4%)         | 0.000*          |
| Spanish                           | 0                  | 12 (66.7%)            | 0                  | 12 (12.6%)         |                 |
| Mammogram Frequency               |                    |                       |                    |                    |                 |
| Insufficiently                    | 11 (32.4%)         | 3 (16.7%)             | 8 (18.6%)          | 22 (23.2%)         | 0.14            |
| Biennially                        | 6 (17.7%)          | 7 (38.9%)             | 19 (44.2%)         | 32 (33.7%)         |                 |
| Annually                          | 17 (50.0%)         | 8 (44.4%)             | 16 (37.2%)         | 41 (43.2%)         |                 |



Note. FPL = Federal poverty level.

\*  $p < 0.05$ .

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 2**  
Odds Ratios and 95% Confidence Intervals for Mammogram Frequency<sup>†</sup>, *n* = 95, Philadelphia, PA, 2010–2013

| Variables                         | Mammogram Screening at Least Biennially Compared to Insufficiently Screened |          | Mammogram Screening Annually Compared to Insufficiently Screened |          |
|-----------------------------------|---|----------|--|----------|
|                                   | OR (95% CI)   | <i>p</i> | OR (95% CI)  | <i>p</i> |
| Race/Ethnicity                    |   |          |  |          |
| White                             | 1.0   |          | 1.0  |          |
| Hispanic                          | 9.5 (1.0–91.9)  | 0.05*    | 0.5 (0.3–41.8)   | 0.29     |
| Black                             | 5.5 (1.0–28.0)  | 0.05*    | 1.8 (0.3–10.6)   | 0.49     |
| Living Arrangement                |   |          |  |          |
| Family/alone                      | 1.0   |          | 1.0  |          |
| Intermediate Care Facility        | 5.62 (0.4–77.0)   | 0.196    | 4.20 (0.4–43.0)  | 0.226    |
| Community Living Arrangement      | 5.69 (0.8–38.2)   | 0.053    | 11.3 (1.78–71.8)   | 0.010**  |
| Neighborhood Socioeconomic Status |   |          |  |          |
| 0–20% households below FPL        | 7.8 (1.0–79.9)  | 0.08     | 7.8 (0.7–79.9)   | 0.08     |
| 20–30% households below FPL       | 4.9 (0.3–69.0)  | 0.24     | 4.9 (0.3–69.0)   | 0.24     |
| 30%+ households below FPL         | 1.0   |          | 1.0  |          |
| Age in 2010                       |   |          |  |          |
| 40–49                             | 1.0   |          | 1.0  |          |
| 50–70                             | 2.9 (0.7–12.1)  | 0.149    | 6.3 (1.5–27.7)   | 0.014**  |
| ID Impairment Severity            |   |          |  |          |
| Mild Impairment                   | 19.8 (2.6–148.1)  | 0.004**  | 9.1 (1.3–64.9)   | 0.028*   |
| Moderate Impairment               | 13.8 (1.6–119.7)  | 0.017*   | 16.5 (2.0–133.6)   | 0.010*   |
| Severe impairment                 | 1.0   |          | 1.0  |          |

Note. FPL = Federal poverty level.

\* *p* < 0.05.

\*\* *p* < 0.01.

<sup>†</sup> Adjusted variables were race/ethnicity, living arrangement, zip code poverty level, age, and ID impairment severity.