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A longitudinal assessment of adherence to breast and cervical cancer screening recommendations among women with and without intellectual disability☆

Xinling Xu[a], **Suzanne W. McDermott**[a,*], **Joshua R. Mann**[b], **James W. Hardin**[a], **Chelsea B. Deroche**[c], **Dianna D. Carroll**[d,e], and **Elizabeth A. Courtney-Long**[d]

[a]University of South Carolina, Arnold School of Public Health, Department of Epidemiology and Biostatistics, 915 Greene Street, Columbia, SC 29208, United States

[b]University of Mississippi Medical Center, Department of Preventive Medicine, 2500 North State Street, Jackson, MS 39216, United States

[c]University of Missouri Columbia, School of Medicine, Biostatistics and Research Design Unit, Health Management and Informatics Office of Medical Research, One Hospital Drive, Columbia, MO 65212, United States

[d]Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability, Disability and Health Branch, Atlanta, GA, United States

[e]Commissioned Corps, U.S. Public Health Service, Atlanta, GA, United States

Abstract

Each year in the United States, about 4000 deaths are attributed to cervical cancer, and over 40,000 deaths are attributed to breast cancer (U.S. Cancer Statistics Working Group, 2015). The purpose of this study was to identify predictors of full, partial, and no screening for breast and cervical cancer among women with and without intellectual disability (ID) who are within the age group for screening recommended by the U.S. Preventive Service Task Force (USPSTF), while accounting for changes in recommendations over the study period. Women with ID and an age matched comparison group of women without ID were identified using merged South Carolina Medicaid and Medicare files from 2000 to 2010. The sample consisted of 9406 and 16,806 women for mammography screening and Papanicolaou (Pap) testing adherence, respectively. We estimated multinomial logistic regression models and determined that women with ID were significantly less likely than women without ID to be fully adherent compared to no screening with mammography recommendations (adjusted odds ratio [AOR]: 0.63, 95% confidence interval [CI] 0.55–0.72), and Pap testing recommendations (AOR: 0.17, 95% CI 0.16–0.19). For the 70%

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*Corresponding author. smcdermo@mailbox.sc.edu (S.W. McDermott).

Conflict of interest

The authors declare there is no conflict of interest.

Transparency document

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of women with ID for whom we had residential information, those who lived in a group home, medical facility, or supervised community living setting were more likely to be fully adherent with both preventive services than those living alone or with family members. For both outcomes, women residing in a supervised nonmedical community living setting had the highest odds of full adherence, adjusting for other covariates.

Keywords

Breast cancer; Cervical cancer; Intellectual disabilities; Papanicolaou test; Mammography; Health care disparities

1. Introduction

There is a growing body of evidence that people with intellectual disability (ID) are at risk of health care disparities, unmet medical needs, and reduced life expectancy compared to the general population (Anderson et al., 2013; Krahn and Fox, 2014; Fenton et al., 2003; Hayden et al., 2005; Kancherla et al., 2013; Morgan et al., 2012; Salvador-Carulla and Symonds, 2016; Heslop and Glover, 2015; Lauer and McCallion, 2015). Recent reports by the United States Public Health Service and the Institute of Medicine identify a number of potential explanations for health disparities for individuals with ID, such as poor access to primary care, failure to include people with ID in public health programs and prevention activities, and insufficient education of health care providers (Krahn and Fox, 2014; Hayden et al., 2005; U.S. Public Health Service (USPHS), 2002, 2005; Krahn et al., 2006; Bershadsky et al., 2012). In evaluating disparities in preventive health care for people with ID, rates of screening for cancer are useful measures because there are screening guidelines from the United States Preventive Services Task Force (USPSTF) (2017a). Two cancer types for which screening is recommended are cervical and breast cancer in women. Although USPSTF recommendations were updated for cervical cancer screening in 2012, during 2000–2010 (the data years used in this study), the recommendations shown in Table 1 were in place for women of average risk.

In terms of susceptibility to cervical cancer, studies about the sexual experience of women with ID indicate lower rates of sexual activity than in the general population (Servais et al., 2002; Gust et al., 2003). On the other hand, individuals with intellectual disability are at increased risk of sexual victimization (Morano, 2001) which can also result in HPV infection a precursor of cervical cancer. We are unaware of any studies describing the prevalence of HPV infection in women with ID, though there is some evidence that women with ID or other developmental disabilities may be less likely to have abnormal results from Pap testing (Kavoussi et al., 2009; Quint and Elkins, 1997; Jaffe et al., 2002). Current guidelines in the US do not exclude this population from recommended screening (United States Preventive Services Task Force (USPSTF), 2017b).

There is evidence of disparities in screening for cervical and breast cancer among women with ID. A review of research conducted in Europe, Ireland, the United Kingdom, and Canada revealed reduced rates of cervical and breast cancer screening in women with ID (Reidy et al., 2014). Another study of 380 women in Western Australia, only 35% of women

with ID underwent mammography compared to 55% of women without ID (Sullivan et al., 2003).

There are at least two potential explanations as to why a smaller proportion of women with ID would not be up to date with cervical or breast cancer screening. One possibility is that doctors face challenges with time management and communication in their care of patients with ID and therefore do not always recommend screening to this group of women (Weedon et al., 2015). The other possibility is that women with ID may be unaware of the need for screening or they or their caregivers anticipate the Pap test and mammogram will cause distress (Greenwood et al., 2014).

It is not known whether and to what degree the level of full adherence with breast and cervical cancer screening guidelines over time differs for women with ID compared to women without ID. To gain insight into the relative contribution of non-screening versus inadequate screening to disparities in overall screening rates, it is necessary to follow women for a period of time that spans more than one recommended screening interval. In this way, women can be categorized into three groups regarding of their adherence to cervical and breast cancer screening: full adherence, partial adherence, and no screening. The primary goal of this study is to examine cervical and breast cancer screening adherence over time among women with ID compared to those without ID. As part of this goal, we wanted to examine predictors of full and partial screening adherence. In particular, we anticipated that residential type could be associated with differential levels of screening since women living in medically supervised settings, including Intermediate Care Facilities for people with ID (ICF/IDs), receive assistance from staff members who facilitate interactions with the health care system.

2. Methods

2.1. Sample

We used data from 2000 to 2010 South Carolina Medicaid claims and other administrative data housed at the South Carolina Revenue and Fiscal Affairs Office as well as South Carolina Medicare claims records processed by Centers for Medicare and Medicaid Services and housed at the Research Data Assistance Center (ResDAC).

We identified women with ID using diagnostic International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes:(317, mild intellectual disability; 318.0, moderate intellectual disability; 318.1, severe intellectual disability; 318.2, profound intellectual disability; and 319, unspecified intellectual disability). These data were merged using a unique identifier variable to determine those women covered by either Medicaid or Medicare. These government programs provide health insurance primarily for the elderly and for those with low incomes, respectively, and also include pathways for disability-related eligibility for each program regardless of age. The sample consisted of women who were 16–60 years of age for Pap testing (n= 17,656) and 36–69 years of age for mammography screening (n = 10,105) in 2000, and were continuously enrolled in either insurance over years 2000–2010 (at least 11 months of enrollment each calendar year). These age ranges were chosen to ensure that women recommended for screenings had at

least 4 and 6 years of eligible enrollment of mammography and Pap testing, respectively. 'Years of eligible enrollment' was defined as years in which a woman was recommended to have the specific preventive screening. We then excluded women with diagnoses of breast, cervical, or endometrial cancer (n = 699 mammography; n = 850 Pap test) based on ICD-9-CM codes from the final analyses because, for these women, mammography screening or Pap testing might not have been for screening purposes. We did not exclude women with a hysterectomy from the cervical cancer screening, since some of them might have remaining cervical stump. However, we conducted an additional sensitivity analysis by estimating the coefficients of the same models including these women and found similar results to those done with the women excluded (results not shown).

The final sample size of women with ID was 2912 women for mammography screening and 5490 women for Pap testing. A comparison group of women without ID (using an approximate 2:1 ratio) was created matched on age to those with ID (n = 6494 mammography; n = 11,316 Pap test).

2.2. Dependent variables

The dependent variables were receipt of mammography screening and Pap testing and were determined by appropriate billing codes (Table 2). These were further categorized, by three levels: full adherence, partial adherence, and no screening. *Full adherence* was defined as a woman's having received all of the screening tests required to meet USPSTF recommendations across all years of eligible enrollment. *Partial adherence* was defined as a having at least one screening test but less than the number required for full adherence to the USPSTF screening recommendations for the entire time period. *No screening* was defined as women who failed to receive any screening tests during the eligible enrollment years. For both tests, women were given a 6-month margin after the scheduled test date for their screenings to be considered adherent. As suggested in previous studies, women can be off schedule for a variety of reasons, such as back-logs in screening test appointments (Partin et al., 1998) therefore, having a 6-month extension to the screening recommendation allowed for late appointments.

2.3. Independent variables

The independent variables in our analyses consisted of: ID status (with or without ID), centered baseline age at year 2000, the squared term of the centered baseline age at year 2000, insurance category (Medicaid only, Medicare only, or Medicaid and Medicare), centered eligible years (continuous variable, for mammography screening: 4–11 years; for Pap testing: 6–11 years), the squared term of centered eligible years, and residential neighborhood (urban, suburban, or rural). We categorized residential neighborhood by linking billing ZIP Codes with Rural-Urban Commuting Area (RUCA) codes, using the file provided by the WWAMI Rural Health Research Center (Hart et al., 2005). In our analyses, we used the baseline neighborhood of residence at year 2000.

Information about type of residence for the women with ID enrolled in Medicaid was available from the South Carolina Department of Disabilities and Special Needs (DDSN) for 71.0% of the women for the mammography screening analyses and for 75.9% of women for

the Pap testing analyses. First residential type recorded by the DDSN during the study period was considered to be the residence for the entire study period, as other analyses using this data source have shown that individuals typically move within a similar category of residential type, rather than between types (data not shown but available from authors). Women were categorized as living in one of four distinct types of residential groups, using the DDSN electronic data file: alone or with family, in a group home (such as a private boarding home or an assisted living facility), in a medical facility (such as an intermediate care facility for individuals with ID or a nursing facility), or in a community living setting (such as supervised living programs or community training homes) where women live in a homelike environment with intermittent supervision of disability agency staff.

2.4. Statistical analysis

We determined screening test adherence for women with ID and those without, stratified by screening test group (i.e., mammogram or Pap test). We estimated multinomial logistic regression models for our data. Multinomial logistic regression is used when modeling responses with more than two levels, and it is a simple extension of binary logistic regression (Elkin, 2012). By using this method, we were able to evaluate the screening pattern by different adherence levels, an improvement over the standard logistic regression. The reference group of the response was no screening in all models. For each screening test, two sets of estimated coefficients were obtained for full adherence versus no screening and partial adherence versus no screening. While models in previous studies focused on binary responses, our use of a three level response provided an innovative approach for analyzing screening service data. Statistical significance was determined at $p < 0.05$. We used SAS, version 9.4 (SAS Institute, Cary, NC) for all statistical analyses. The University of South Carolina Institutional Review Board determined that the proposed activity was exempt from the Protection of Human Subjects Regulation (45 CFR 46.102).

3. Results

Descriptive information for all individuals is shown in Table 3. Most women lived in an urban setting (72.5% and 72.4% of women with ID and 77.5% and 76.1% for women without ID in the mammography screening and Pap testing groups, respectively). For the women with ID, the largest proportion lived alone or with family members (32.8% for the mammography screening group and 46.2% for the Pap testing group), followed by unknown type of residence.

Overall, during the study period, 31.0% of the women with ID and 22.7% of the women without ID had no screening using mammography. Full adherence for mammography was 22.2% for women with ID and 20.9% for women without ID. A total of 35.2% of the women with ID and 14.6% of the women without ID had no screening with Pap testing. Full adherence for Pap testing was 24.3% for women with ID and 46.3% for women without ID.

3.1. Mammography screening

Compared to no screening, women with ID are less likely to be either partially or fully adherent to recommendations. Specifically, the adjusted odds ratio for women with ID to be

fully adherent was 0.63 (95% confidence interval [CI] 0.55, 0.72), while the adjusted odds ratio for women with ID to be partially adherent was 0.58 (95% CI 0.52, 0.65). Women who were dually insured by Medicare and Medicaid had 3.72-fold (95% CI 2.83, 4.89) odds of full adherence and 1.40-fold (95% CI 1.07, 1.83) odds of partial adherence (Table 4).

3.2. Pap testing

Compared to no screening, the odds of being fully or partially adherent were lower for women with ID than for women without ID (full adherence AOR 0.17, 95% CI 0.16, 0.19; partial adherence AOR 0.37, 95% CI 0.34, 0.40), after adjusting for covariates. Women who were dually insured by Medicare and Medicaid had 4.70-fold (95% CI 3.64, 6.08) odds of full adherence and 3.01-fold (95% CI 2.34, 3.86) odds of partial adherence (Table 4).

3.3. Type of residence

We examined the relationship between type of residence, when available, and insurance category only among the women with ID. These associations were highly significant (Chi-squared test: $p < 0.0001$). Therefore, we included the interaction term of the insurance category and the type of residence in the models. For both screening tests, after adjusting for other covariates, women with ID who lived in a group home, medical facility, or supervised community living setting were more likely to be fully adherent with both preventive services versus not being screened, compared with those who lived alone or with family (Table 5). For both screening tests, women residing in a supervised community living setting had the highest odds of full adherence. The proportions of women with full adherence to mammography screening and Pap testing were 41.36% and 35.10%, respectively, for those who resided a supervised community setting, compared to 11.64% and 18.71%, respectively, among the women living alone or with family. The odds ratios of being fully adherent with mammography and Pap testing were 9.97 (95% CI 6.81, 14.60), and 4.14 (95% CI 3.24, 5.29), respectively, among women enrolled in Medicaid only. The odds ratios for full adherence in women residing in a supervised community setting were even higher for women were dually insured (Table 5).

4. Discussion

There are a number of potential explanations for disparities in screening for women with ID; some relate to general health disparities experienced for the population with ID, while others are likely specific to Pap testing and mammography. For instance, women with ID might have difficulty grasping the abstract concept of risk, and the physical discomfort of these screening procedures might be difficult to accept (Parish and Saville, 2006; Wilkinson et al., 2011a). Thus, for women with mild and moderate ID who do not have a legal guardian, they could refuse screening, and for women with severe of profound ID, who have a legal guardian the issue of consenting for the screening is left to the guardian. Challenges, such as needing more assistance with aspects of the examination and feeling embarrassed about the experience, might contribute to lower screening rates (Greenwood et al., 2014; Wilkinson et al., 2011a, 2011b). Additionally, difficulty navigating the health care system also might play a role; in one study, women with ID who had the assistance of a nurse to coordinate their health care had higher mammography screening rates (Wilkinson et al., 2011a, 2011b).

For both screening tests, a recent systematic review highlighted the importance of a physician's recommendation for screening to increase cancer screening rates (Peterson et al., 2016). Although it is unknown how effective these recommendations are for women with ID it has been documented that communication between obstetric and gynecologic providers and women with ID is problematic (Phillips et al., 2004; Dovey and Webb, 2000), and therefore, education of physicians about effective communication with women who have ID may have the potential to reduce disparities. Full adherence rates for Pap testing may also be impacted by previous difficulties due to anxiety or coexisting physical impairments (Tyler et al., 2010; Gajdosik and Cicirello, 2002; Krigger, 2006; Rapp and Torres, 2000). These concerns may be magnified in the context of doubts among physicians about the need for Pap testing due to low rates of cytologic abnormalities in women with ID (Quint and Elkins, 1997; Jaffe et al., 2002; Parish, 2013).

Among women with ID, those living in supervised nonmedical community settings and, to a lesser degree, those living in group homes or medical facilities had h higher odds of both mammography screening and Pap testing compared to women who lived alone or with family. The higher odds of mammography screening and Pap testing among women who lived in supervised settings might reflect disability service organizations having policies and procedures for regular physician contact that can result in provision of preventive services. Some disability service agencies identify physicians in their community who are attuned to the needs of women with ID, and these providers use strategies to reduce the anxiety during the testing. Additional research is needed to describe specific barriers that might result in reduced rates of screening among women with ID who live alone or with family members.

Our estimated prevalence rates of full adherence with mammography and Pap testing were low for both women with ID and those without ID, relative to other estimates using population-based data. An analysis of 2013 South Carolina Behavioral Risk Factor Surveillance System (BRFSS) data revealed that approximately three in four women reported mammography in the preceding 2 years, and approximately four in five women reported Pap testing within the preceding 3 years (South Carolina Behavioral Risk Factor Surveilance System (BRFSS), 2013).

There are several potential explanations for these discrepancies. One is that the BRFSS relies on self-report, so over-reporting is possible. It is also possible that billing records may underreport screening (for example, if for some reason the service is not billed to Medicaid or Medicare). In addition, women with ID may be at lower risk for cervical cancer, based on lower rates of sexual activity, and this could change the physician's assessment of the benefit risk ratio for screening. Finally, the refusal rate for screening might be higher in women with ID, although to our knowledge this has not been empirically documented. There were limitations to our study. First, we relied on diagnostic codes to identify women with ID, so there is potential for some misclassification of ID status. Second, we did not subset the women into mild, moderate, severe and profound groups of ID and the findings could vary between these subgroups. Third, although the information about residential setting was available for a substantial portion of the women, we did not know the quality or the types of caregiving supports provided or if the women who resided at home lived alone or with family. Fourth, this study was limited to women who had Medicaid or Medicare health

insurance, and the findings are not generalizable for uninsured women. Also, we used baseline residence for examining the impact of residential type; we did not account for change of address during the study period. Finally, our study was limited to women residing in South Carolina, which has a different racial and ethnic makeup and a different proportion of low SES households than the US as a whole. Thus, these findings might not be generalizable to other states or be considered nationally representative.

Our study also had important strengths. One was that our use of billing claims data allowed for identification of women with ID, a group on which little to no data are available in national and state health surveys. Use of Medicare or Medicaid claims, the primary insurers of people with lifelong disability captures most women with ID. In South Carolina the National Breast and Cervical Cancer Early Detection Program only covers women with no insurance coverage so it is unlikely we missed many women with ID. This could lead to more conservative estimates of full and partial adherence for both groups of women, but we would not expect these issues to affect women with and without ID differently. Claims data is not reliant on self-report or family report, which are both subject to recall bias. Second, by using longitudinal data, we were able to examine adherence over time, which allowed us to identify individuals who were fully or partially adherent. In contrast, cross-sectional data allow for identifying adherence only as a binary outcome and might misclassify those as fully adherent if they happened to receive one screening service during the survey period but did not follow through with recommended screenings subsequently. Such individuals were identified as partially adherent in our study, which allowed us to consider those who were not screened at all over the 11-year data period as a distinct group. However, future research needs to investigate the different risk factors for full and partial adherence, and assess differences across subsets of ID based on severity (mild, moderate, severe and profound). Our study addresses the cross-sectional limitation of prior research by assessing screening adherence among a population over a period of time, while accounting for changes in the USPSTF screening recommendations. However, we did not know all the factors associated with failure to obtain initial screening and the factors associated with rescreening.

5. Conclusion

This study found that women with ID were less likely than women without ID to be fully or partially adherent with screening recommendations for breast and cervical cancer over time. Our longitudinal analysis allowed us to identify a partially screened group of women who might have a different profile from women who are not screened. A second important finding was that women with ID living in nonmedical community settings that received some support from a disability agency were most likely to be fully adherent with screening, especially mammography, than those living in other residential settings. The subgroup least likely to be partially or fully adherent with screening, were those who alone or with relatives. To improve breast and cervical cancer screening adherence among women with ID, strategies and approaches that identify and address the specific barriers encountered by women with ID who live alone or with family.

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References

Anderson LL, Humphries K, McDermott S, Marks B, Sisarak J, Larson S. The state of the science of health and wellness for adults with intellectual and developmental disabilities. Intellect. Dev. Disabil. 2013; 51(5):385–398. http://dx.doi.org/10.14440/jbm.2015.54.A. [PubMed: 24303825]

Bershadsky, J., Taub, S., Engler, J., Moseley, CR., Lakin, KC., Stancliffe, RJ., Larson, S., Ticha, R., Bailey, C., Bradley, V. Public Health Rep. Vol. 127. Washington, D.C.: 2012. Place of residence and preventive health care for intellectual and developmental disabilities services recipients in 20 states; p. 475-485.1974. (Retrieved from http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3407847&tool=pmcentrez&rendertype=abstract)

Dovey S, Webb OJ. General practitioners' perception of their role in care for people with intellectual disability. J. Intellect. Disabil. Res. 2000; 44(5):553–561. [PubMed: 11079352]

Elkin, E. Beyond Binary Outcomes: PROC LOGISTIC to Model Ordinal and Nominal Dependent Variables. SAS Global Forum; 2012.

Fenton SJ, Hood H, Holder M, May PB Jr, Mouradian WE. The American Academy of Developmental Medicine and Dentistry: eliminating health disparities for individuals with mental retardation and other developmental disabilities. J. Dent. Educ. 2003; 67(12):1337–1344. (Retrieved from http://www.jdentaled.org/content/67/12/1337.full.pdf). [PubMed: 14733266]

Gajdosik C, Cicirello N. Secondary conditions of the musculoskeletal system in adolescents and adults with cerebral palsy. Phys. Occup. Ther. Pediatr. 2002; 21(4):49–68.

Greenwood NW, Dreyfus D, Wilkinson J. More than just a mammogram: breast cancer screening perspectives of relatives of women with intellectual disability. Intellect. Dev. Disabil. 2014; 52(6):444–455. http://dx.doi.org/10.1352/1934-9556-52.6.444. [PubMed: 25409131]

Gust DA, Wang SA, Grot J, Ransom R, Levine WC. National survey of sexual behavior and sexual behavior policies in facilities for individuals with mental regardation/developmental disabilities. Ment. Retard. 2003; 41(5):365–373. [PubMed: 12962532]

Hart LG, Larson EH, Lishner DM. Rural definitions for health policy and research. Am. J. Public Health. 2005; 95(7):1149–1155. http://dx.doi.org/10.2105/AJPH.2004.042432. [PubMed: 15983270]

Hayden MF, Kim SH, DePaepe P. Health status, utilization patterns, and outcomes of persons with intellectual disabilities: review of the literature. Ment. Retard. 2005; 43(3):175–195. http://dx.doi.org/10.1352/0047-6765(2005)43[175:HSUPAO]2.0.CO;2. [PubMed: 15882081]

Heslop, P., Glover, G. Mortality of People With Intellectual Disabilities in England: A Comparison of Data from Existing Sources. 2015. p. 414-422.http://dx.doi.org/10.1111/jar.12192

Jaffe JS, Timell AM, Eisenberg MS, Chambers JT. Low prevalence of abnormal cervical cytology in an institutionalized population with intellectual disability. J. Intellect. Disabil. Res. 2002; 46(7):569–574. http://dx.doi.org/10.1046/j.1365-2788.2002.00439.x. [PubMed: 12354313]

Kancherla V, Van Naarden Braun K, Yeargin-Allsopp M. Dental care among young adults with intellectual disability. Res. Dev. Disabil. 2013; 34(5):1630–1641. http://dx.doi.org/10.1016/j.ridd.2013.02.006. [PubMed: 23501584]

Kavoussi SK, Smith YR, Ernst SD, Quint EH. Cervical cancer screening with liquid cytology in women with developmental disabilities. J. Women's Health (Larchmt). 2009 Jan-Feb;18(1):115–118. [PubMed: 19072727]

Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? J. Appl. Res. Intellect. Disabil. 2014; 27(5):431–446. http://dx.doi.org/10.1111/jar.12067. [PubMed: 23913632]

Krahn GL, Hammond L, Turner A. A cascade of disparities: health and healthcare access for people with intellectual disabilities. Ment. Retard. Dev. Disabil. Res. Rev. 2006; 12:70–82. http://dx.doi.org/10.1002/mrdd.20098. [PubMed: 16435327]

Krigger KW. Cerebral palsy: an overview. Am. Fam. Physician. 2006; 73(1):91–100. [PubMed: 16417071]

Lauer E, McCallion P. Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. J. Appl. Res. Intellect. Disabil. 2015; 28(5):394–405. http://dx.doi.org/10.1111/jar.12191. [PubMed: 25994364]

Morano JP. Sexual abuse of the mentally retarded patient: medical and legal analysis for the primary care physician. Prim Care Companion. J. Clin. Psychiatry. 2001; 3(3):126–135.

Morgan JP, Minihan PM, Stark PC, Finkelman MD, Yantsides KE, Park A, Nobles CJ, Tao W, Must A. The oral health status of 4732 adults with intellectual and developmental disabilities. J. Am. Dent. Assoc. 2012; 143(8):838–846. http://dx.doi.org/10.14219/jada.archive.2012.0288. [PubMed: 22855898]

Parish SL. Determinants of cervical cancer screening among women with intellectual disabilities: evidence from medical records. Public Health Rep. 2013 Dec.128:519–526. [PubMed: 24179263]

Parish SL, Saville AW. Women with cognitive limitations living in the community: evidence of disability-based disparities in health care. Ment. Retard. 2006; 44(4):249–259. http://dx.doi.org/10.1352/0047-6765(2006)44[249:WWCLLI]2.0.CO;2. [PubMed: 16834462]

Partin MR, Casey-Paal AL, Slater JS, Korn JE. Measuring mammography compliance: lessons learned from a survival analysis of screening behavior. Cancer Epidemiol. Biomark. Prev. 1998; 7:681–687.

Peterson EB, Ostroff JS, DuHamel KN, D'Agostino TA, Hernandez M, Canzona MR, Bylund CL. Impact of provider-patient communication on cancer screening adherence: a systematic review. Prev. Med. 2016; 93(12):96–105. http://dx.doi.org/10.1016/S0091-7435(03)00177-4. [PubMed: 27687535]

Phillips A, Morrison J, Davis RW. General practitioners' educational needs in intellectual disability health. J. Intellect. Disabil. Res. 2004; 48(2):142–149. [PubMed: 14723656]

Quint EH, Elkins TE. Cervical cytology in women with mental retardation. Obstet. Gynecol. 1997; 89(1):123–126. [PubMed: 8990452]

Rapp C, Torres M. The adult with cerebral palsy. Arch. Fam. Med. 2000; 9:1063–1087.

Reidy M, Denieffe S, Foran S. Cancer screening in women with intellectual disabilities: an Irish perspective. J. Intellect. Disabil. 2014; 18(1):51–60. http://dx.doi.org/10.1177/1744629514521067. [PubMed: 24591427]

ResDAC. Research Data Assistance Center. http://www.resdac.org

Salvador-Carulla L, Symonds S. Health services use and costs in people with intellectual disability: building a context knowledge base for evidence-informed policy. Curr. Opin. Psychiatry. 2016; 29(2):89–94. [PubMed: 26808613]

Servais L, Jacques D, Leach R, Conod L, Hoyois P, Dan B, Roussaux JP. Contraception of women with intellectual disability: prevalence and determinants. J. Intellect. Disabil. Res. 2002; 46(2): 108–119. [PubMed: 11869381]

South Carolina Behavioral Risk Factor Surveilance System (BRFSS). [Last accessed January 22, 2017] Disability and Health in South Carolina - A 2013 Bahavioral Risk Factor Surveillance System Report. 2013. http://www.scdhec.gov/library/CR-010034_2013.pdf

Sullivan SG, Glasson EJ, Hussain R, Petterson BA, Slack-Smith LM, Montgomery PD, Bittles AH. Breast cancer and the uptake of mammography screening services by women with intellectual disabilities. Prev. Med. 2003; 37(5):507–512. http://dx.doi.org/10.1016/S0091-7435(03)00177-4. [PubMed: 14572435]

Tyler CV, Zyzanski SJ, Panaite V, Council L. Nursing perspectives on cancer screening in adults with intellectual and other developmental disabilities. Intellect. Dev. Disabil. 2010; 48(4):271–277. http://dx.doi.org/10.1352/1934-9556-48.4.271. [PubMed: 20722477]

U.S. Public Health Service (USPHS). Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. U.S. Department of Health and Human Services, Office of the

Surgeon General; Washington, DC: 2002. Closing the Gap: A National Blueprint for Improving the Health of Individuals With Mental Retardation.

U.S. Public Health Service (USPHS). U.S. Department of Health and Human Services, Office of the Surgeon General; Washington, DC: 2005. The Surgeon General's Call to Action to Improve the Health and Wellness of People with Disabilities.

United States Preventive Services Task Force (USPSTF). [Last accessed 2017a January 22] http://www.uspreventiveservicestaskforce.org/

United States Preventive Services Task Force (USPSTF). Final Recommendation Statement, Cervical Cancer: Screening (Clinical Considerations). 2017. Retrieved from https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/cervical-cancer-screening#clinical-considerations

Weedon D, Wilson B, Jones KB, Bilder D. Care of adults with intellectual and developmental disabilities: developmental disabilities. FP Essent. 2015; 12(439):11–19.

Wilkinson JE, Deis CE, Bowen DJ, Bokhour BG. “It's easier said than done”: perspectives on mammography from women with intellectual disabilities. Ann. Fam. Med. 2011a; 9(2):142–147. http://dx.doi.org/10.1370/afm.1231. [PubMed: 21403141]

Wilkinson JE, Lauer E, Freund KM, Rosen AK. Determinants of mammography in women with intellectual disabilities. J. Am. Board Fam. Med. 2011b; 24(6):693–703. http://dx.doi.org/10.3122/jabfm.2011.06.110095. [PubMed: 22086812]

Table 1

Screening recommendations during study period.

Cervical cancer	Breast cancer
2000–2002: Papanicolaou (Pap) testing (United States Preventive Services Task Force (USPSTF) (2017a); Servais et al., 2002) at least every 3 years for women 18–65 years of age	2000–2001: Mammography (Gust et al., 2003) at least every 2 years for women 50–69 years of age
2003–2010: Pap testing at least every 3 years for women 21–65 years of age.	2002–2007: Mammography at least every 2 years for women 40–74 years of age
	2008–2010: Mammography at least every 2 years for women 50–74 years of age.

Table 2

Codes for identifying mammogram and Papanicolaou test screening procedures.

Name of codes	ICD-9-CM codes	CPT® codes	HCPCS codes
Mammogram	V76.10, V76.11, V76.12, V76.19	77051,77052, 77055–77059	G8111, G0202, G0204, G0206
Papanicolaou test	V67.01, V72.31, V76.2, V76.47	88141–88143, 88147, 88148, 88150, 88152–88154, 88164–88167, 88174, 88175	P3000, P3001, Q0091, G0123, G0124, G0143–G0145, G0147, G0148

Abbreviations: ICD-9, International Classification of Diseases, Ninth Revision, Clinical Modification; CPT®, Current Procedural Terminology; HCPCS, Healthcare Common Procedure Coding System.

Table 3

Characteristics of women with or without intellectual disability by cancer screening cohort group, South Carolina Medicaid and Medicare medical claim records, 2000–2010.

Characteristic	Mammography		Papanicolau testing	
	Women with ID (n = 2912)	Women without ID (n = 6494)	Women with ID (n = 5490)	Women without ID (n = 11,316)
Response				
Full adherence	22.2%	20.9%	24.3%	46.3%
Partial adherence	46.8%	56.4%	40.5%	39.1%
No screening	31.0%	22.7%	35.2%	14.6%
Insurance category				
Medicaid only	78.1%	83.5%	83.8%	89.6%
Medicare only	16.2%	0.4%	9.7%	1.0%
Medicare and Medicaid	5.7%	16.1%	6.5%	9.4%
Insurance category				
Urban	72.5%	77.5%	72.4%	76.1%
Suburban	20.1%	16.8%	19.5%	17.5%
Rural	7.4%	5.7%	8.1%	6.4%
Insurance category				
Alone/with family	32.8%	–	46.2%	–
Group home	4.9%	–	3.5%	–
Medical facility	12.7%	–	9.1%	–
Community living	20.7%	–	17.2%	–
Unknown	29.0%	–	24.1%	–
Mean age[a]	46.7 (8.4)	47.3 (8.6)	34.5 (12.0)	35.5 (12.1)
Eligible years[a]	8.4 (2.4)	8.5 (2.4)	10.5 (1.4)	10.3 (1.3)

Abbreviation: ID, intellectual disability.

[a]Continuous variables with sample means and standard errors.

Table 4

Women with intellectual disability (ID) compared to women without ID, adjusted[a] odds ratios for full and partial adherence versus no screening to U.S. Preventive Services Task Force recommendations for mammography and Papanicolaou tests, South Carolina Medicaid and Medicare Medical Claim Records, 2000–2010.

	Mammography				Pap testing			
	Full adherence vs. no screening		Partial adherence vs. no screening		Full adherence vs. no screening		Partial adherence vs. no screening	
Covariates	**AOR**	**95% CI**	**AOR**	**95% CI**	**AOR**	**95% CI**	**AOR**	**95% CI**
ID vs. comparison group	0.63	(0.55, 0.72)	0.58	(0.52, 0.65)	0.17	(0.16, 0.19)	0.37	(0.34, 0.40)
Medicare and Medicaid vs. Medicaid only	3.72	(2.83, 4.89)	1.40	(1.07, 1.83)	4.70	(3.64, 6.08)	3.01	(2.34, 3.86)
Medicare only vs. Medicaid only	1.15	(0.96, 1.39)	0.95	(0.81, 1.11)	0.68	(0.58, 0.79)	1.06	(0.92, 1.23)
Live in suburban area vs. live in urban area	0.85	(0.72, 1.00)	0.92	(0.81, 1.05)	0.99	(0.89, 1.11)	1.04	(0.93, 1.16)
Live in rural area vs. live in urban area	0.79	(0.62, 1.00)	0.74	(0.60, 0.91)	0.86	(0.72, 1.02)	0.93	(0.79, 1.09)

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval; ID, intellectual disability.

[a]Adjusted for all covariates shown in the table, and mean age, squared term of mean age, eligibility years, squared term of eligibility years.

Table 5

Women with intellectual disability (ID) only, adjusted[a] odds ratios for full and partial adherence with screening recommendations by type of residence, South Carolina Medicaid and Medicare Medical Claim Records, 2000–2010.

Type of residence	Adherence level	Adjusted odds ratio (Medicaid; n = 1629)	95% confidence interval	Adjusted odds ratio (dual insurance; n = 439)	95% confidence interval
Mammography					
Group home	Full adherence vs. no screening	4.40	(2.34, 8.29)	7.52	(2.24, 25.25)
Medical facility		4.82	(3.12, 7.45)	9.20	(3.94, 21.44)
Community living		9.97	(6.81, 14.60)	24.60	(10.17, 59.47)
Alone/with family		1.00	REF	1.00	REF
Group home	Partial adherence vs. no screening	3.08	(1.81, 5.23)	1.96	(0.64, 6.14)
Medical facility		2.19	(1.51, 3.16)	1.57	(0.75, 3.26)
Community living		3.81	(2.72, 5.33)	3.29	(1.51, 7.16)
Alone/with family		1.00	REF	1.00	REF
Type of residence	Adherence level	Adjusted odds ratio (Medicaid; n = 3675)	95% confidence interval	Adjusted odds ratio (dual insurance; n = 493)	95% confidence interval
Pap testing					
Group home	Full adherence vs. no screening	2.50	(1.58, 3.97)	6.27	(1.95, 20.16)
Medical facility		2.04	(1.51, 2.76)	22.73	(8.95, 57.69)
Community living		4.14	(3.24, 5.29)	27.30	(11.97, 62.23)
Alone/with family		1.00	REF	1.00	REF
Group home	Partial adherence vs. no screening	1.86	(1.25, 2.76)	4.11	(1.41, 11.97)
Medical facility		1.50	(1.16, 1.94)	8.01	(3.34, 19.20)
Community living		2.96	(2.39, 3.67)	7.58	(3.52, 16.30)
Alone/with family		1.00	REF	1.00	REF

Abbreviations: REF, reference group.

[a]Adjusted for all covariates: mean age, squared term of mean age, eligibility years, squared term of eligibility years, and residential neighborhood category.