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

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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% 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.



## 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.

☆ Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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**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<br>2008–2010: Mammography at least every 2 years for women 50–74 years of age. |

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).