# IS IT RAMPS, RECOMMENDATIONS, OR SOMETHING ELSE? DISABILITY AND ACCESS TO PAP SMEARS AMONG U.S. WOMEN

Julia A. Rivera Drew, Population Studies and Training Center, *Brown University* Susan E. Short, Population Studies and Training Center, *Brown University* 

## ABSTRACT

CONTEXT: Ever-sexually active women are at risk of cervical cancer, one of the most common female reproductive cancers. Although nearly 20% of adult women in the U.S. report a disability, and disability has been shown to affect health care access, the relationship between disability and receipt of a Pap smear remains little explored.

METHODS: Using nationally representative data from the 2000 and 2005 National Health Interview Surveys we investigate the relationship between disability and cervical cancer screening for 20,907 women between 21 and 64 years of age. With logistic regression analyses we examine receipt of a Pap smear and receipt of a recommendation for a Pap smear.

RESULTS: Disability, including mobility, sensory, mental, cognitive and social limitations, reduces the likelihood of Pap smear receipt in the year prior to the survey, net of other factors, including age, income, insurance, and a usual source of care. Women with disabilities were just as likely, if not more likely, to receive a Pap smear recommendation. However, conditional on recommendation receipt, they were less likely to receive a Pap smear. Among those not receiving a Pap smear, 25% of women with disabilities cited cost or insurance as the primary reason, twice the percentage of women without disabilities.

CONCLUSIONS: Disability is negatively associated with cervical cancer screening. Multiple types of disability, not only those arising from mobility limitations, impede access, suggesting barriers beyond the built environment. Addressing the needs of women with disabilities is relevant to efforts to reduce inequalities in reproductive health care access.

Cervical cancer is one of the most common female reproductive cancers.<sup>1</sup> Sexually transmitted infections associated with strains of the human Papilloma virus (HPV) are responsible for most cervical cancer cases,<sup>2</sup> making exposure to sexual activity the primary risk factor for developing cervical cancer. Women are at risk of cervical cancer if they are currently sexually active or have ever been sexually active. Recent data published by the Centers for Disease Control estimate that 26.8%, or 24.9 million, U.S. women between the ages of 14 and 59 are infected with HPV.<sup>3</sup>

Fortunately, of all the cancers affecting female reproductive organs, cervical cancer is one of the most preventable. Preventive screening for cervical cancer is most widely done with the Papanicolaou test, or Pap smear<sup>4,5</sup> which has been credited with an estimated 70% decrease in the cervical cancer mortality rate over the past 40 years.<sup>6</sup> Despite this decline, as of 2002, cervical cancer remained the 10<sup>th</sup> leading cause of cancer-related death among women, and the 5<sup>th</sup> leading cause of cancer-related death among women.<sup>4</sup>

Most women who develop cervical cancer today have not received cervical cancer screening within the recommended intervals.<sup>4</sup> Thus, identifying barriers to receipt of cervical cancer screening is critical to promoting the reproductive health of U.S. women. In this paper we focus on one potential barrier, having a disabling condition. We investigate how disability may be related to Pap smear receipt. While preventive care is important for all, some researchers argue that access to preventive services is especially important for individuals with disabilities because they experience a "thinner margin of health," making them more vulnerable to significant medical problems than individuals without disabilities.<sup>7,8</sup>

Approximately 20% of U.S. adults 18 years of age and older live with at least one disabling condition.<sup>9</sup> As recent studies have highlighted that people with disabilities may have less access to health care, particularly preventive care,<sup>7,10</sup> disability has emerged as an axis of stratification in

understandings of health disparities. Indeed, in 2005, the Surgeon General of the United States called for the need to "break down barriers to health and wellness for people with disabilities" and issued *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities.*<sup>9</sup> This paper, using nationally representative data from 2000 and 2005, seeks to broaden our understanding of the connection between disability and Pap smear receipt among women in the U.S.

## BACKGROUND

Limited prior research on the relationship between disability status and cervical cancer screening uses nationally representative data. Two review studies on correlates of preventive cancer screenings do suggest a negative relationship between disability status and Pap smear receipt,<sup>8,11</sup> however, disability is not a central focus in either study. In both studies, measures of disability emphasize mobility impairment as captured by Activities of Daily Living (ADLs), capturing one dimension of a range of physical, mental, and social impairments that might interfere with health care receipt.

Studies that focus specifically on disability tend to rely on specialized samples, rather than nationally representative data. A study by Ramirez and colleagues,<sup>12</sup> based on data from the 2001 California Health Interview Study, finds that women 18 and older with disabilities are 17% less likely than women 18 and older without disabilities to receive a Pap smear in the three years preceding the survey. Further, they find that women with disabilities are less likely than women without disabilities to receive a doctor recommendation for a Pap smear. Other studies with specialized populations, such as women with mobility impairments recruited from independent living centers, also suggest a negative association between physical disability and cervical cancer screening.<sup>13</sup> A study that focused specifically on disability and used nationally representative data from 1994 suggested that Pap smear receipt was less likely when women had major lower extremity mobility difficulties.<sup>8</sup> Although the study did not

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focus on cervical cancer specifically, it provides the best evidence to date that some types of disability are connected to Pap smear receipt in the U.S.

Our research builds upon and extends this previous work on disability and cervical cancer screening in several ways. First, using the nationally representative National Health Interview Survey from 2000 and 2005, we focus specifically on disability and Pap smear receipt. We examine the relationship in a regression context and attend to the temporal ordering of disability and Pap smear receipt. Most previous work has been based on bivariate associations<sup>14</sup> or regression analyses that consider disability status at the time of data collection and receipt of a Pap smear in the three years prior to data collection.<sup>8,11,12,15</sup> In addition, our paper empirically explores two factors suggested to be relevant to disability and health care receipt. The first is the built environment, which refers to the created physical environment as a potential barrier to access for women with disability. The second is clinical treatment, which refers to the possibility that women with disabilities and women without disabilities are treated differently in medical settings by health care providers. Finally, using the cancer supplement from 2005, we explore reasons for non-receipt of a Pap smear as reported by women, and ask whether reasons for non-receipt of a Pap smear differ for women with and without disabilities.

#### **CONCEPTUALIZING DISABILITY**

Most conceptualizations of disability today recognize that individuals experience chronic illnesses or impairments that become disabling when they attempt to fulfill social roles such as student, worker, parent, woman, and citizen in the existing built, political, economic, social, and cultural environments. This conceptualization is represented in the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) which breaks disability down into three conceptual domains: 1) impairments – indicating deviations from the population norm or losses in body structures or body functions due to some underlying pathology; 2) activities – referring to an individual's ability to perform a task; and 3) participation – defined broadly as "involvement in life situations." <sup>16</sup>

While the WHO recognizes disability to include limitations that prevent the fulfillment of social roles, standard measurement of disability in surveys, including the NHIS, relies on reported functional limitations. Accordingly, we measure disability based on limitations due to diagnosed mental or physical conditions lasting for at least one year prior to the survey.

In measuring disability, we distinguish between four combinations of disabling conditions: 1) mobility impairment; 2) sensory, mental, cognitive, and/or social impairment; 3) both mobility and a sensory, mental, cognitive, and/or social impairment; and 4) other physical impairment unrelated to mobility (limitations in grasping, carrying, or pushing).<sup>a</sup> By relying on functional limitations to the exclusions of social roles we do not capture variations in the everyday meaning of limitations in individual lives; however, we are able to capture broad categories of limitation that we believe are relevant to understanding differences in Pap smear use. Further, in using the National Health Interview Survey, we use a nationally representative data set that is well-respected for its measurement of disability in the working aged population. Notably, the National Health Interview Survey has been used as a reference for assessment of disability-related measures in other survey data.<sup>17</sup>

## **BARRIERS TO SCREENING**

Two factors, the built environment and clinical factors, have been identified as particularly salient for understanding the barriers experienced by women with disabilities in accessing health care.<sup>8,12</sup> We review each as it relates to Pap smear receipt.

#### The Built Environment

The term "built environment" usually refers to human-made physical features of the environment. It can affect cervical cancer screening receipt among women with disabilities insofar as it impedes women's physical access to buildings that house medical personnel. Buildings that lack elevators or ramps, have halls or doors that are too narrow to permit easy passage, may limit physical access. In addition, offices in which existing medical equipment and technologies, especially examination tables and diagnostic tools, do not fit or measure "non-standard" bodies can limit access. Finally, some have proposed that lack of accessible and convenient transportation to and from medical offices constitutes a barrier to the built environment.<sup>7</sup>

Although arguments have been made about the importance of the "built environment" in previous research, most of these arguments are based on research that has focused solely on women with mobility limitations,<sup>8,13,18,19</sup> or that has operationalized "disability" as the sum of mostly physical limitations, such as ADLs or the ability to grasp and carry objects or climb stairs.<sup>11,15</sup>

Our approach is different. By defining disability to include mobility impairment as well as sensory, mental, cognitive, and social impairment, and recognizing that individuals may experience multiple forms of disability at the same time, we consider disability more broadly. In particular, we are able to explore simultaneously whether mobility and non-mobility limitations are associated with Pap smear access. Finding that mobility impairments are negatively associated with Pap smear receipt would be consistent with built environment explanations; finding that multiple forms of disability impairment are relevant to Pap smear access would suggest that factors beyond the built environment are relevant to Pap smear receipt.

#### **Clinical Factors**

A second explanation for observed disparities centers on "clinical factors,"<sup>12</sup> which have also been referred to as "process barriers."<sup>19</sup> Explanations that privilege clinical barriers emphasize the knowledge, attitudes, and practices of providers, and how they may affect the likelihood that women with disabling conditions receive a Pap smear.

Medical providers may lack knowledge about the sexual functioning and the reproductive health needs of women with disabilities.<sup>15,18,20</sup> They also can make erroneous assumptions about the desire or ability of women with disabilities to have sex or bear children, or may hold negative attitudes about the appropriateness of sexual activity or childbearing.<sup>18,21-24</sup> Finally, medical personnel may provide care to women with disabilities that is too "disability-focused," care that views disabling conditions as the object of treatment, rather than other health concerns.<sup>7,10</sup> Such care likely diminishes the likelihood that individuals with disabilities will receive preventive services unrelated to their disabling condition.

All of these factors would lead us to expect that women with disabilities would be less likely than other women to receive a recommendation for a Pap smear. Indeed, Ramirez and colleagues<sup>12</sup> found that, in California, women with disabilities were less likely than other women to receive a physician recommendation for a Pap smear, and suggested that lack of recommendation could be a significant reason women with disabilities were less likely to receive Pap smears. Our analysis explores the relationship between disability and recommendation empirically with nationally representative data. Further, it examines this relationship for women with all types of disability, expanding the focus beyond mobility limitations.

#### **DATA AND METHODS**

Data for this study come from the 2000 and 2005 National Health Interview Survey (NHIS) focal adult samples. The NHIS, nationally representative annual household surveys administered in person by

interviewers trained by the U.S. Census Bureau, are regarded as one of the best sources of information about the health and well-being of the American people. Within each household sampled, one adult and one child were randomly selected from each family to complete a more in-depth questionnaire about health and health care utilization.<sup>b</sup> The NHIS, which has a response rate of 72% for focal adults in 2000 and 69% in 2005, is particularly well suited for our research because it includes information on health, health care access and utilization, and social and demographic characteristics.<sup>25,26</sup> We use the 2000 and 2005 NHIS because in these years, the Cancer Control Module was included with the core NHIS questionnaire. This module was administered to all women completing the in-depth focal adult questionnaire. Women were asked about Pap smear recommendation and receipt, as well as the primary reason for non-receipt, if a Pap smear had not been received within the recommended interval.<sup>25,26</sup>

The sample includes women between the ages of 21 and 64, the recommended age range for regular Pap smears. Pooling data from 2000 and 2005 allows for exploration of change over time in likelihood of Pap smear access among U.S. women. The sample is limited to women expected to be at risk of receiving routine preventive cervical cancer screening, and includes 20,907 women: 3,709 women with disabilities and 17,198 women without disabilities. Women who have been diagnosed with genitourinary cancer (cervical, uterine, or ovarian) or reported a genitourinary problem, or who have undergone a hysterectomy, are excluded from the sample.

We model two outcomes, receipt of a Pap smear and receipt of a physician recommendation for a Pap smear. Receipt of a Pap smear is a dichotomous variable indicating a Pap smear was received during the year prior to the survey. The recommended interval between Pap smears has long been one year. In 2002, the American Cancer Society, and in 2003, the American College of Obstetricians and Gynecologists and the U.S. Preventive Services Task Force issued new guidelines. Although the guidelines differ slightly, the recommendation on frequency of Pap smear continues to be one year for

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women before age 30, but was changed to two to three years for women 31-69 who have had three consecutive negative tests and are not at high risk. The revised guidelines have been controversial, with some calling for the continuance of one year intervals due to the relatively high rate of false negatives using the Pap smear test.<sup>5</sup> Preliminary evidence suggests adherence to the new guidelines has been low with some medical professionals preferring that their patients continue to receive screenings at one year intervals.<sup>26</sup> Nonetheless, we construct our measure of age so that women ages 21 to 29 are grouped separately. In addition, because this change in guidelines for women at age 30 and older occurred between the two time points in our analysis, we examined interactions between the year of survey and age of women. Results did not support their inclusion and we present the more parsimonious additive specifications in our tables of results.

Finally, receipt of a Pap smear recommendation is a dichotomous variable indicating whether, within the past year, a woman received a recommendation from a health care provider to receive a Pap smear. Information on Pap smear recommendation is available only for the full sample of women in 2005 and the analysis is limited accordingly. The sample for this analysis includes 9,661 women, after dropping 541 cases with missing values (5.3%) on recommendation. We explored whether disability was significantly related to the probability of missing values on recommendation receipt in supplemental analyses (not shown), but found no association, and no change in any substantive conclusions.

As described earlier, disability is measured by reported functional limitations due to diagnosed mental or physical conditions lasting for at least one year prior to the survey as summarized in four mutually exclusive categories: 1) mobility impairment; 2) sensory, mental, cognitive, and/or social impairment; 3) both mobility and a sensory, mental, cognitive, and/or social impairment; and 4) other physical impairment unrelated to mobility. All models control for factors traditionally linked to reproductive health care access, including age, race and ethnicity, marital status, having had at least one

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birth, region, number of doctor visits, type of health insurance, and usual source of care. Type of health insurance distinguishes between the uninsured, those with public insurance, and those with private insurance. Usual source of care distinguishes between those who indicated that they had a place to go when sick or in need of health advice that was not a hospital emergency room or outpatient department.

Missing data on independent variables is trivial, less than 1% of the sample on any individual characteristic, with the exception of income. About 21% of the sample is missing data on income. We explored multiple approaches to handling the missing income data, and assessed the sensitivity of model results under each approach. Specifically, we compared unweighted and weighted models using complete case analysis, single imputation using mean values on income, multiple imputation using the Markov Chain Monte Carlo (MCMC) method, and multiple imputation using chained equations.<sup>28,29</sup> Results were robust across all of the strategies for handling missing data, and we present results based on multiple imputation using chained equations. We judge this method to have advantage over the others in that it easily facilitates the adjustment of variance estimates for complex survey design, as well as the subsetting the data, as recommended by NCHS.<sup>26</sup>

## RESULTS

Table 1 reports basic descriptive statistics for the full sample by disability status. Overall, 75% of able-boded women reported receiving a Pap smear in the previous year compared to 68% of women with disabilities. However, this difference is plausibly associated with factors other than disability. Women with disabilities are older on average than women without disabilities, with a mean age of 45 compared to 38 years. Women with disabilities are also poorer, have lower levels of education, are less likely to have private insurance, and report more doctor visits in the past year. They are especially likely to be on public health insurance, with 30% of women with disabilities receiving public health insurance

compared to 8% of women without disabilities. Women with public health insurance are most likely to be Medicaid beneficiaries because of the age range (21-64) represented in the sample. Notably, roughly three-quarters of women, irrespective of disability, reported having had at least one birth.

Table 2 provides detail on type of disability. Women may have more than one type of disability and these overlaps are recognized in the four mutually exclusive categories presented. Mobility disability is the most common form of disability with 13% of women 21-64 years reporting disability due a mobility limitation, and about half in combination with sensory, mental, cognitive, or social impairment. Some 3% of women experience sensory, mental, cognitive, or social disability, without mobility impairment. Finally, about 2% of women report physical disabilities that do not involve mobility.

#### [TABLES 1 AND 2 ABOUT HERE]

Table 3 reports results on the relationship between disability status and Pap smear receipt. Model 1 indicates that, net of other factors, women with disability are less likely to have received a Pap smear in the year prior to the survey. Receipt of a Pap smear was more likely in 2000 than in 2005, and more likely among younger women than among older women. We also tested whether the likelihood of receiving a Pap smear among women with disability was different in 2005 than in 2000 (not shown), but found no support for any difference. Model 2 explores differences by type of disability. It suggests that mobility limitations are indeed negatively associated with receipt of a Pap smear. However, women with sensory, social, mental, or cognitive impairment also experience disadvantage. Moreover, women with some of the most severe disabilities, were more disadvantaged than women with only mobility limitations in terms of Pap smear receipt (p<.05). Taken together, these results suggest that while the built environment may well limit women with disabilities in accessing preventive care, such as Pap smear receipt, disability may also limit receipt of preventive care for reasons other than the built environment.

### [TABLES 3 AND 4 ABOUT HERE]

In Table 4 we consider clinical factors. Specifically, we consider whether, net of other factors, women with disability are as likely as other women to receive a recommendation for a Pap smear. We limit this analysis to 2005, the year in which all women are asked about recommendations. Table 4 shows four specifications. The first two predict receipt of a recommendation for a Pap smear. The second two predict receipt of a Pap smear among women who have received a recommendation.

As shown in the first specification, overall, women with disabilities appear no more or less likely to receive a recommendation for a Pap smear in the year prior to the survey compared to other women, net of other factors, including number of doctor visits. However, results by disability type, as shown in the second specification, are suggestive of differences by type of disability. Notably, women with mobility limitations may be more likely to receive a recommendation than women without disabilities. We see no effect for other types of disability, but interpret null results cautiously due the smaller frequencies in some categories.

The third specification in Table 4 explores whether, among women who receive a recommendation, disability affects the likelihood of receipt of a Pap smear. Results suggest that women with disabilities are *less* likely than other women with a recommendation to receive a Pap smear. Notably, as shown in the fourth specification, the reduced likelihood holds for women with mobility impairments as well as those with sensory, mental, cognitive, or social impairments. As might be expected, less educated women, never-married women, and uninsured women are also less likely to receive a Pap smear conditional on receipt of a recommendation. Younger women, Black and Hispanic women, and women with a usual source of care, are more likely to report receiving a Pap smear if they

had received a recommendation. These results confirm that, net of controls, clinical factors are relevant to Pap smear receipt, but suggest that researchers look beyond recommendations from clinical providers to understand such differences.

#### Reasons for Pap Smear Non-Receipt

Finally, the cancer supplement of the NHIS in 2005 allows us to explore the reasons women give for non-receipt of a Pap smear. Figure 1 presents a summary of reasons for non-receipt by disability status for women who had not received a Pap smear in the three years preceding the survey. To ensure disability preceded the period of Pap smear receipt, the definition of disability is limited to the onset of disabling conditions three or more years prior to the survey.

Overall, reasons for non-receipt are similar for women with and without disabilities. For all women, the two most frequently cited reasons for Pap smear non-receipt, accounting for about 75% of non-receipt, are "no reason, not experiencing any problems, or putting it off" and "cost or no insurance." About two-thirds of women without disabilities and nearly half of women with disabilities indicated no specific reason. About one-quarter of women with disabilities, and 12% of women without disabilities, cited cost or insurance reasons. Notably, women with disabilities were twice as likely to cite cost or insurance reasons compared to women without disabilities. It was not clear whether lack of knowledge about Pap smears contributed to the large number of women who gave no reason for non-receipt.<sup>30</sup>

## [FIGURE 1 ABOUT HERE]

#### DISCUSSION

The analyses presented in this paper explore the correlates of Pap smear receipt for a nationally representative sample of women in 2000 and 2005 with an emphasis on the role of disability. Results

indicate that women with disabilities, both mobility and other disabilities, were less likely than women without disabilities to receive a Pap smear in the previous year, net of other characteristics. We found little support for the argument that women with disabilities were less likely to receive a recommendation for a Pap smear, however. Nonetheless, among women who received a recommendation, women with disabilities were less likely to receive a Pap smear.

When we explored the reasons women gave for non-compliance, one of the most frequently cited reasons was inability to access care because of cost or being uninsured, and women with disabilities were twice as likely to give this reason than women without disabilities. These results are notable in light of government programs such as the Centers for Disease Control's National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which promotes and pays for breast and cervical cancer screening for uninsured and low-income women.<sup>31,32</sup>

A closer look at women in the NHIS who reported not receiving Pap smears due to cost, lack of insurance, or no doctor indicates that they were likely to be middle-class, uninsured, and report at least \$500 of annual medical expenditures. Women with disabilities were more likely to be insured than women without disabilities, but nonetheless, had higher annual medical costs. In their review of the organization and financing of health care for individuals with disabilities, DeJong and colleagues<sup>7</sup> note that Medicaid has proven to be a better provider for the health services needs of individuals with disabilities than either Medicare or private insurers (p. 272), but that necessary preventive care tends to fall by the wayside for individuals with disabilities may become frustrated with organizational features of health care financing that leave them financially drained after paying for major disability-related episodes of care, which suggests that they may decide to forego preventive care as a cost-saving strategy. More recent reports indicate that delay in seeking needed medical care may be growing for the

population as a whole; the uninsured and insured, many of whom experience higher deductibles and copayments, delay care due to cost as well logistic barriers such as trouble getting through to a doctor's office on the telephone or difficulty scheduling timely appointments.<sup>33</sup> Our findings, when considered in the context of these other reports, suggest that future work should incorporate health systems barriers, as well as measures of the built environment or clinical factors, to understand barriers to cervical cancer screening and other preventive reproductive health services for women with disabilities.

Our paper focuses on disability and receipt of a Pap smear, however the analysis can inform understandings of access to reproductive health care more broadly, where access to health care is understood to mean an individual's capacity to obtain appropriate, quality medical care from competent health care providers in a timely and efficient manner. One of the primary reasons the Pap smear has been credited with such a dramatic decline in cervical cancer incidence is that it is relatively inexpensive and easy to administer, and can be accessed in a variety of locations, through a general practitioner, OB/GYN, or nurse practitioner.<sup>6</sup> Additionally, there exist widely accepted guidelines recommending cervical cancer screening at regular intervals for *all* women between the ages of 21 and 64 who have not undergone a hysterectomy. Further, though it is feasible that limited social networks can act as barriers to knowledge of specific health care services, the probability that limited social networks act as a barrier to knowledge about cervical cancer screening is minimized by the age of the test (it was widely introduced in the 1950s), and the government programs designed to meet the needs of uninsured and low-income women.<sup>6,31,32</sup> Thus, utilization of Pap smears within recommended intervals likely captures access to basic reproductive health care reasonably well.

In closing, we emphasize that women most at risk for developing cervical cancer are those who do not receive screenings within recommended intervals, thus making it imperative that we identify and examine underserved groups. Women with disabilities are one such group. Although recent years have

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brought the possibility of alternative prevention in the form of an HPV vaccine, according to the CDC, about 30% of cervical cancers will not be prevented by the current vaccine, and all vaccinated women should thus receive regular Pap smears.<sup>34</sup> Financial costs to screening with a Pap smear are low, and the real or perceived costs women experience need to be addressed so as to protect all women from unnecessary risk.

## REFERENCES

- 1. US Cancer Statistics Working Group. 2005. *United States Cancer Statistics: 2002 Incidence and Mortality*. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention, and National Cancer Prevention Institute.
- 2. Mayo Clinic Staff. Retrieved September 15, 2006. "Cervical Cancer." http://www.mayoclinic.com/health/cervical-cancer/DS00167
- Dunne, E.F., E.R. Unger, M. Sternberg, G. McQuillan, D.C. Swan, S.S. Patel, and L.E. Markowitz. 2007. "Prevalence of HPV Infection among Females in the United States." *Journal of the American Medical Association* 297(8): 813-819.
- 4. Berg, A.O. 2004. "Screening for Cervical Cancer: Recommendations and Rationale: United States Preventive Services Task Force". *Internet Journal of Oncology* 2(1): 22-36.
- Duberstein, L., J.J. Frost, C. Sten, and C. Dailard. 2006. "Provision of Contraceptive and Related Services by Publicly Funded Family Planning Clinics, 2003." *Perspectives on Sexual and Reproductive Health*, 38(3): 139-147.
- 6. Kuo, D.Y. and G.L. Goldberg. 2003. "Screening of Cervical Cancer: Where Do We Go from Here?" *Cancer Investigation*, 21(1): 157-161.
- DeJong, G., S.E. Palsbo, P.W. Beatty, G.C. Jones, T. Kroll, and M.T. Neri. 2002. "The Organization and Financing of Health Services for Persons with Disabilities". *Milbank Quarterly* 80(2): 261-301.

- 8. Iezzoni, L.I., E.P. McCarthy, R.B. Davis and H. Siebens. 2000. "Mobility Impairments and Use of Screening and Preventive Services". *American Journal of Public Health* 90(6): 955-961.
- 9. Carmona, R.H. and J. Cabe. 2005. "Improving the Health and Wellness of Persons with Disabilities: A Call to Action." *American Journal of Public Health* 95(11): 1883.
- 10. Albrecht, G.L. 2001. "Rationing Health Care to Disabled People". *Sociology of Health and Illness* 23(5): 654-677.
- 11. Hewitt, M., S.S. Devesa and N. Breen. 2004. "Cervical Cancer Screening among US Women: Analyses of the 2000 National Health Interview Survey". *Preventive Medicine* 39: 270-278.
- Ramirez, A., G.C. Farmer, D. Grant and T. Papachristou. 2005. "Disability and Preventive Cancer Screening: Results from the 2001 California Health Interview Survey". *American Journal of Public Health* 95(11): 2057-2064.
- Nosek, M.A. and C.A. Howland. 1997. "Breast and Cervical Cancer Screening among Women with Physical Disabilities." *Archives of Physical Medicine and Rehabilitation* 78(12, Supplement 5): S39-S44.
- Swan, J., N. Breen, R.J. Coates, B.K. Rimer, and N.C. Lee. 2003. "Progress in Cancer Screening Practices in the United States: Results from the 2000 National Health Interview Survey." *Cancer* 97(6): 1528-1540.
- 15. Diab, M.E. and M.V. Johnston. 2004. "Relationships between Level of Disability and Receipt of Preventive Health Services". *Archives of Physical Medicine and Rehabilitation* 85(5): 749-757.
- 16. World Health Organization. 2001. *International Classification of Functioning, Disability, and Health*. Geneva: World Health Organization, p.10.
- 17. Burkhauser, R.V., M.C. Daly, A.J. Houtenville, N. Nargis. 2002. "Self-Reported Work-Limitation Data: What They Can and Cannot Tell Us." *Demography* 39(3): 541-555.
- Nosek, M.A., D.H. Rintala, M.E. Young, C.C. Foley, C. Howland, G.F. Chanpong, D. Rossi, J. Bennett, and K.L. Meroney. 2001. "National Study of Women with Physical Disabilities: Final Report". *Sexuality and Disability* 13(1): 5-40.
- Kroll, T., G.C. Jones, M. Kehn, and M.T. Neri. 2006. "Barriers and Strategies Affecting the Utilization of Primary Preventive Services for People with Physical Disabilities: A Qualitative Inquiry." *Health and Social Care in the Community* 14(4): 284-293.
- 20. Smeltzer, S.C. 2006. "Preventive Health Screening for Breast and Cervical Cancer and Osteoporosis in Women with Physical Disabilities". *Family and Community Health* 29(1S): 35S-43S.

- 21. Havercamp, S.M., D. Scandlin, and M. Roth. 2004. "Health Disparities among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina". *Public Health Reports* 119: 418-426.
- 22. O'Toole, C.J. and T. Doe. 2002. "Sexuality and Disabled Parents with Disabled Children." *Sexuality and Disability* 20(1): 89-101.
- 23. Milligan, M.S. and A.H. Neufeldt. 2001. "The Myth of Asexuality: A Survey of Social and Empirical Evidence." *Sexuality and Disability* 19(2): 91-109.
- 24. Block, P. 2000. "Sexuality, Fertility, and Danger: Twentieth-Century Images of Women with Cognitive Disabilities." *Sexuality and Disability* 18(4): 239-254.
- 25. National Center for Health Statistics. 2002. *Data File Documentation, National Health Interview Survey, 2000 (machine readable data file and documentation).* Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention.
- 26. National Center for Health Statistics. 2006. *Data File Documentation, National Health Interview Survey, 2005 (machine readable data file and documentation)*. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention.
- Saint, M., G. Gildengorin and G.F. Sawaya. 2005. "Current Cervical Neoplasia Screening Practices of Obstetrician/Gynecologists in the US." *American Journal of Obstetrics and Gynecology* 192: 414-21.
- Horton, N.J. and K.P. Kleinman. 2007. "Much Ado About Nothing: A Comparison of Missing Data Methods and Software to Fit Incomplete Data Regression Models." *The American Statistician* 61(1): 79-90.
- 29. Royston, P. 2005. "Multiple Imputation of Missing Values: Update." The Stata Journal 5(2): 1-14.
- 30. Radecki, C., H.C. Pearson Breitkopf, and D.M. Breitkopf. 2005. "Poor Knowledge Regarding the Pap Test among Low-Income Women Undergoing Routine Screening." *Perspectives on Sexual and Reproductive Health*, 37(2): 78-84.
- 31. CDC. 2009a. National Breast and Cervical Cancer Early Detection Program. Accessed at <a href="http://www.cdc.gov/cancer/nbccedp/http://www.cdc.gov/cancer/nbccedp/">http://www.cdc.gov/cancer/nbccedp/</a>.
- 32. National Women's Law Center and Henry J. Kaiser Family Foundation. 2003. *Women's Access to Health Care: A State-Level Analysis of Key Health Policies*. Menlo Park, CA: Henry J. Kaiser Family Foundation.
- 33. New York Times. 2008. Editorial titled "Maybe I'll Get Better on My Own." Accessed electronically on June 30, 2008 at <u>http://www.nytimes.com/2008/06/30/opinion/30mon2.html</u>.

- 34. CDC. 2009b. HPV Fact Sheet. Accessed at <u>http://www.cdc.gov/std/Hpv/STDFact-HPV</u> vaccine.htm#hpvvac7.
- 35. Meyers, A.R. and E.M. Andresen. 2000. "Enabling Our Instruments: Accommodation, Universal Design, and Access to Participation in Research." *Archives of Physical Medicine and Rehabilitation* 81(12, Part 2): S5-S9.

# TABLES

	Women with	Women without
	Disabilities	Disabilities
Variables	Mean (SD)	Mean (SD)
Pap smear receipt in past year***	0.68 (0.47)	0.75 (0.43)
Pap smear recommendation in past year (year 2005 only)***	0.58 (0.49)	0.53 (0.50)
Age		
Mean in years***	45.3 (11.4)	38.1 (11.1)
21 to 29***	0.12 (0.32)	0.27 (0.44)
30 to 39***	0.19 (0.39)	0.31 (0.46) 0.42 (0.49)
40 to 64***	0.69 (0.46)	
Race/Ethnicity		
Hispanic***	0.17 (0.37)	0.21 (0.41)
White*	0.62 (0.49)	0.60 (0.49)
Black***	0.18 (0.38)	0.15 (0.36)
Other	0.04 (0.19)	0.04 (0.20)
Education	× /	× /
Less than HS***	0.23 (0.42)	0.15 (0.35)
HS Graduate***	0.30 (0.46)	0.26 (0.44)
Some College	0.29 (0.46)	0.30 (0.46)
College Graduate***	0.18 (0.38)	0.29 (0.46)
Income to Poverty Ratio	( )	
<100% of the FPL***	0.22 (0.42)	0.11 (0.31)
<300% of the FPL***	0.31 (0.46)	0.29 (0.45)
>=300% of the FPL***	0.29 (0.46)	0.41 (0.49)
Missing income***	0.17 (0.38)	0.20 (0.40)
Marital Status	( )	
Married/Cohabiting***	0.47 (0.50)	0.59 (0.49)
Divorced/Widowed/Separated***	0.32 (0.47)	0.19 (0.40)
Never married	0.21 (0.41)	0.22 (0.41)
Has had at least one birth***	0.77 (0.42)	0.72 (0.45)
Region		
Northeast	0.18 (0.38)	0.19 (0.39)
Midwest***	0.25 (0.44)	0.23 (0.42)
South**	0.33 (0.47)	0.36 (0.48)
West	0.23 (0.42)	0.22 (0.42)
Health Insurance Type		
Uninsured	0.18 (0.39)	0.20 (0.40)
Private***	0.52 (0.50)	0.72 (0.45)
Public***	0.30 (0.46)	0.08 (0.27)
Has a usual source of care***	0.86 (0.34)	0.84 (0.37)
Number of Doctor Visits in Past Year		
None***	0.08 (0.28)	0.16 (0.37)
One or two***	0.27 (0.45)	0.49 (0.50)
Three or more***	0.64 (0.48)	0.35 (0.48)
N	3,709	17,198

# Table 1. Descriptive Characteristics by Disability Status among Women 21-64 in the United States

*Note:* \*\*\*p<0.001, \*\*p<0.01, \*p<0.05.

Source: 2000 and 2005 National Health Interview Surveys.

Disability Type	Ν	Mean (SD)
Any	3,709	0.18 (0.38)
Mobility only	1,283	0.06 (0.24)
Mobility and sensory, social, mental, or cognitive	1,464	0.07 (0.26)
Sensory, social, mental, or cognitive, no physical	563	0.03 (0.16)
Other physical, no mobility	399	0.02 (0.14)
Total number of women in sample	20,907	1.00

# Table 2. Disability by Type among Women 21-64 in the United States

Source: 2000 and 2005 National Health Interview Surveys.

	Model One	Model Two	
Predictors	b (SE)	b (SE)	
Intercept	0.09 (0.11)	0.07 (0.11)	
Disability	-0.52 (0.05)***		
Mobility		-0.44 (0.08)***	
Mobility and Sensory,			
Mental, Cognitive, or Social		-0.75 (0.08)***	
Sensory, Mental, Cognitive		× ,	
or Social, No Physical		-0.61 (0.11)***	
Other Physical, no Mobility		-0.04 (0.14)	
No disabilities (ref.)	0	0	
Age	Ū.	° °	
30 to 39	-0.28 (0.07)***	-0.27 (0.07)***	
40 to 64	-0.69 (0.06)***	-0.68 (0.06)***	
21 to 29 (ref.)	0	0	
Race/Ethnicity	v	0	
Hispanic	0.20 (0.07)**	0.19 (0.07)**	
Black	0.52 (0.07)***	0.52 (0.07)***	
Other	-0.65 (0.10)***	-0.65 (0.10)***	
White (ref.)	-0.03 (0.10)	-0.83 (0.10)	
Income to Poverty Ratio	v	0	
<100% of the FPL	-0.19 (0.09)*	-0.19 (0.09)*	
<300% of the FPL	-0.28 (0.06)***	-0.25 (0.06)***	
>=300% of the FPL (ref.)	0	0	
Education	0 50 (0 00)***	0.40.0000	
Less than HS	-0.50 (0.08)***	-0.49 (0.08)***	
HS Graduate	-0.49 (0.06)***	-0.49 (0.06)***	
Some College	-0.25 (0.06)***	-0.25 (0.06)***	
College Graduate (ref.)	0		
Marital Status			
Divorced/ Widowed/ Separated	-0.10 (0.06)	-0.09 (0.05)	
Never Married	-0.53 (0.07)***	-0.53 (0.07)***	
Married/Cohabiting (ref.)	0	0	
Has Had $\geq 1$ Birth	0.28 (0.05)***	0.28 (0.05)***	
Region			
Northeast	0.01 (0.06)	0.01 (0.06)	
Midwest	0.01 (0.06)	0.01 (0.07)	
South	0.01 (0.06)	0.02 (0.06)	
West (ref.)	0	0	
Had a Usual Source of Care	0.48 (0.06)***	0.48 (0.06)***	
Health Insurance Type			
Uninsured	-0.55 (0.06)***	-0.55 (0.06)***	
Public	-0.16 (0.08)*	-0.09 (0.08)	
Private (ref.)	Ò	0	
Number of doctor visits			
No visits (ref.)	0	0	
One or two visits	1.74 (0.06)***	1.74 (0.06)***	
Three or more	2.17 (0.07)***	2.19 (0.07)***	
Survey Year = $2005$	-0.22 (0.04)***	-0.22 (0.04)***	
N	20,907	20,907	
F-test (df)	83.5 (21)	104.66 (26)	
Note: ***p<0.001, **p<0.01, *p<0.05. Set	purce: The 2000 and 2005 National	Health Interview Surveys	

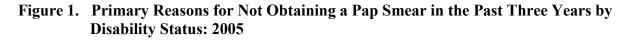
# Table 3. Logistic Regressions Predicting Pap Smear Receipt

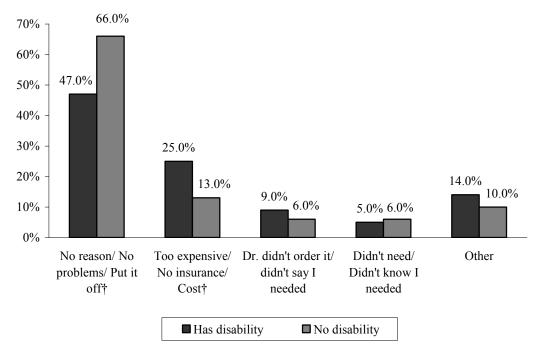
Note: \*\*\*p<0.001, \*\*p<0.01, \*p<0.05. Source: The 2000 and 2005 National Health Interview Surveys.

	Recommenda	ation Receipt	t of a Recommendation: 2005 Pap Receipt, Conditional on Recommendation Receipt		
	Overall disability	Disability type	Overall disability	Disability type	
Predictors	b (SE)	b (SE)	b (SE)	b (SE)	
Intercept	-0.59 (0.13)***	-0.59 (0.14)***	1.15 (0.27)***	1.12 (0.27)***	
Disability	0.12 (0.07)		-0.67 (0.11)***		
Mobility	/	0.21 (0.10)*		-0.65 (0.15)***	
Mobility and Sensory,		( )		( )	
Mental, Cognitive, or Social		0.10 (0.11)		-0.76 (0.15)***	
Sensory, Mental, Cognitive		( )		( )	
or Social, No Physical		-0.17 (0.16)		-0.95 (0.20)***	
Other Physical, no Mobility		0.21 (0.17)		-0.24 (0.26)	
No disabilities (ref.)		Ò		0	
Age					
30 to 39	-0.11 (0.08)	-0.11 (0.08)	-0.30 (0.15)*	-0.28 (0.15)	
40 to 64	-0.11 (0.08)	-0.11 (0.08)	-0.83 (0.14)***	-0.81 (0.14)***	
21 to 29 (ref.)	0	0	0	0	
Race/Ethnicity					
Hispanic	-0.19 (0.08)*	-0.20 (0.08)*	0.33 (0.15)*	0.30 (0.15)*	
Black	-0.07 (0.08)	-0.08 (0.08)	0.67 (0.17)***	0.66 (0.17)***	
Other	-0.23 (0.14)	-0.24 (0.14)*	-0.02 (0.22)	-0.03 (0.22)	
White (ref.)	0	0	0	0	
Income to Pov. Ratio					
<100% of FPL	0.05 (0.10)	0.05 (0.11)	-0.11 (0.19)	-0.06 (0.18)	
<300% of FPL	0.03 (0.06)	0.03 (0.07)	-0.26 (0.11)*	-0.24 (0.12)*	
>=300% of FPL (ref.)	0	0	Ô	0	
Education					
Less than HS	-0.15 (0.11)	-0.15 (0.11)	-0.33 (0.18)	-0.33 (0.18)	
HS Graduate	-0.15 (0.07)*	-0.14 (0.07)	-0.32 (0.13)*	-0.32 (0.13)*	
Some College	-0.13 (0.07)	-0.13 (0.07)	-0.14 (0.13)	-0.14 (0.13)	
College Grad (ref.)	0	0	0	0	
Marital Status					
Divorced/ Wid./ Sep.	-0.02 (0.07)	-0.02 (0.07)	-0.20 (0.12)	-0.20 (0.12)	
Never Married	-0.44 (0.07)***	-0.43 (0.07)***	-0.47 (0.15)**	-0.47 (0.15)**	
Mar./ Cohab. (ref.)	0	0	0	0	
Has Had $\geq 1$ Birth	0.36 (0.07)***	0.36 (0.07)***	0.02 (0.13)	0.02 (0.12)	
Region					
Northeast	0.40 (0.08)***	0.40 (0.08)***	-0.20 (0.13)	-0.20 (0.13)	
Midwest	0.23 (0.08)**	0.23 (0.07)**	-0.06 (0.14)	-0.07 (0.14)	
South	-0.10 (0.07)	-0.10 (0.07)	0.02 (0.13)	0.03 (0.13)	
West (ref.)	0	0	0	0	
Usual Source of Care	0.24 (0.07)**	0.23 (0.08)**	0.33 (0.15)*	0.32 (0.15)*	
Health Insurance					
Uninsured	-0.06 (0.08)	-0.06 (0.08)	-0.71 (0.15)***	-0.71 (0.15)***	
Public	-0.16 (0.10)	-0.14 (0.10)	-0.34 (0.16)*	-0.29 (0.16)	
Private (ref.)	0	0	0	0	
Number of doctor visits					
None (ref.)	0	0	0	0	
One or two	0.58 (0.09)***	0.57 (0.08)***	1.35 (0.14)***	1.37 (0.14)***	
Three or more	0.94 (0.09)***	0.93 (0.08)***	1.77 (0.15)***	1.79 (0.15)***	
N	9,661	9,661	5,698	5,698	
F-test (df)	19.1 (22)	16.3 (25)	16.6 (22)	15.8 (25)	

Table 4.	Logistic Regressions Predicting Receipt of a Recommendation for a Pap Smear
	and Receipt of Pap Smear Conditional on Receipt of a Recommendation: 2005

*Note:* \*\*\*p<0.001, \*\*p<0.01, \*p<0.05., *Source:* 2005 National Health Interview Survey.





*Note:*  $N_{dis} = 325$ ,  $N_{nodis} = 1,183$ . All percentages in figure are population weighted. Responses in 2000 (not shown) and 2005 are not statistically different.

Source: 2005 National Health Interview Survey.

<sup>†</sup>Differences significant at p < 0.001.

Data points for Figure 1 [Not for inclusion in published manuscript]

		No reason/ No problems/ Put it off <sup>†</sup>	Too expensive/ No insurance/ Cost <sup>†</sup>	Dr. didn't order it/ didn't say I needed	Didn't need/ Didn't know I needed	Other
2005	Has disability	0.47	0.25	0.09	0.05	0.14
	No disability	0.66	0.13	0.06	0.06	0.10
2000	Has disability	0.56	0.19	0.07	0.05	0.14
	No disability	0.68	0.13	0.05	0.05	0.08

## NOTES

<sup>a</sup> Respondents with mobility disabilities required help with personal care needs (bathing, feeding, dressing) or had difficulty walking, standing, sitting, stooping, bending, kneeling, or reaching overhead. Respondents with sensory limitation reported having a lot of trouble seeing or hearing, or being blind or deaf. Respondents with a mental or cognitive disability had difficulty remembering or a functional limitation because of mental retardation, depression, substance abuse or another mental or emotional condition. Respondents with a social disability reported problems working, engaging in social or leisure activities like visiting friends or relaxing at home, problems performing household chores or shopping due to a physical, mental or emotional problem. Mental, cognitive, and sensory limitations are similar in that onset tends to be early in the life course (usually before age 30). In addition, medical, state, and educational institutions historically recognized these disabilities in a similar way by creating special residential K-12 schools and enacting restrictive marriage and child custody laws and policies. <sup>b</sup> The NHIS reports that focal adults were randomly selected from the household pool of all eligible adults. As has been explained elsewhere, the sampling of disabled individuals for national research is likely biased despite the use of proxy respondents.<sup>33</sup> It is reasonable to expect given current interview protocols that individuals with significant communication or cognitive disabling conditions are underrepresented. Uncertainty about the exact representation of adults with disabilities is common to research using nationally representative surveys and not unique to this study.