

# Increased Knowledge of Breast and Cervical Cancer Screening Needed Among Women with Developmental Disabilities



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## Overview

Women with developmental disabilities had alarmingly limited knowledge of breast and cervical cancer screening procedures. Rates of knowledge varied by the women's living situations. Women living alone or with a spouse were more informed than women living in residential settings, while women living with family caregivers had the least knowledge.

Health care providers must ensure that they are providing women with disabilities care that is consistent with standard recommendations for preventive screening for all women. Health care providers, service providers, and policymakers should offer activities and programs to inform and engage women with developmental disabilities and their families around preventive health.

Cervical and breast cancer screening help reduce disease and death, but all women do not have equal access to these forms of early detection. In particular, women with developmental disabilities receive these services at a low rate,<sup>1-5</sup> despite the fact that these standard procedures are recommended for all women of a certain age.<sup>6</sup>

The women's lack of knowledge of the cancers or preventive procedures may contribute to these low rates of screening receipt. The American health care system increasingly places the burden on patients to advocate for their own care.<sup>6</sup> To get the best care, patients need to be informed and empowered, including patients with developmental disabilities.<sup>7</sup> Women who do not understand preventive procedures may not receive the care they need. This study examined the extent to which women with developmental disabilities have or lack basic knowledge of cervical and breast cancer screening.

This *Lurie Institute for Disability Policy Brief* reports findings from interviews with 202 women with developmental disabilities across North Carolina. All women lived in community (vs. institutional) settings, although some lived alone or with a spouse, while others lived in residential settings or with family caregivers. We examined the relationship between where women lived and the extent of their knowledge of basic information about breast and cervical cancer and screening procedures.

## Limited Knowledge about Cervical and Breast Cancer Screening

- Overall, women’s knowledge of basic information about breast and cervical cancer screening was alarmingly low. When asked basic questions about mammography, clinical breast exams, and Pap tests, women on average answered fewer than half correctly – 3.9 correct answers out of 9 questions.
- Women knew more about clinical breast exams than about mammography or Pap tests. While 88% knew who should do a breast exam, fewer than 40% of the women could provide broad definitions of mammography or Pap tests.
- Knowledge varied by living situation. Women living alone or with a spouse answered the most questions correctly, averaging 5.5 out of 9. Women in residential facilities answered about half the questions correctly (4.3 out of 9). Women living with family caregivers were least informed, answering on average only 3.3 out of 9 basic questions correctly.
- Women with more severe impairments were less informed about screening than women with less severe impairments. However, even when severity of impairment and age were controlled for, women living with family caregivers knew less about Pap tests and mammography than women in other living situations.

### Summary & Recommendations

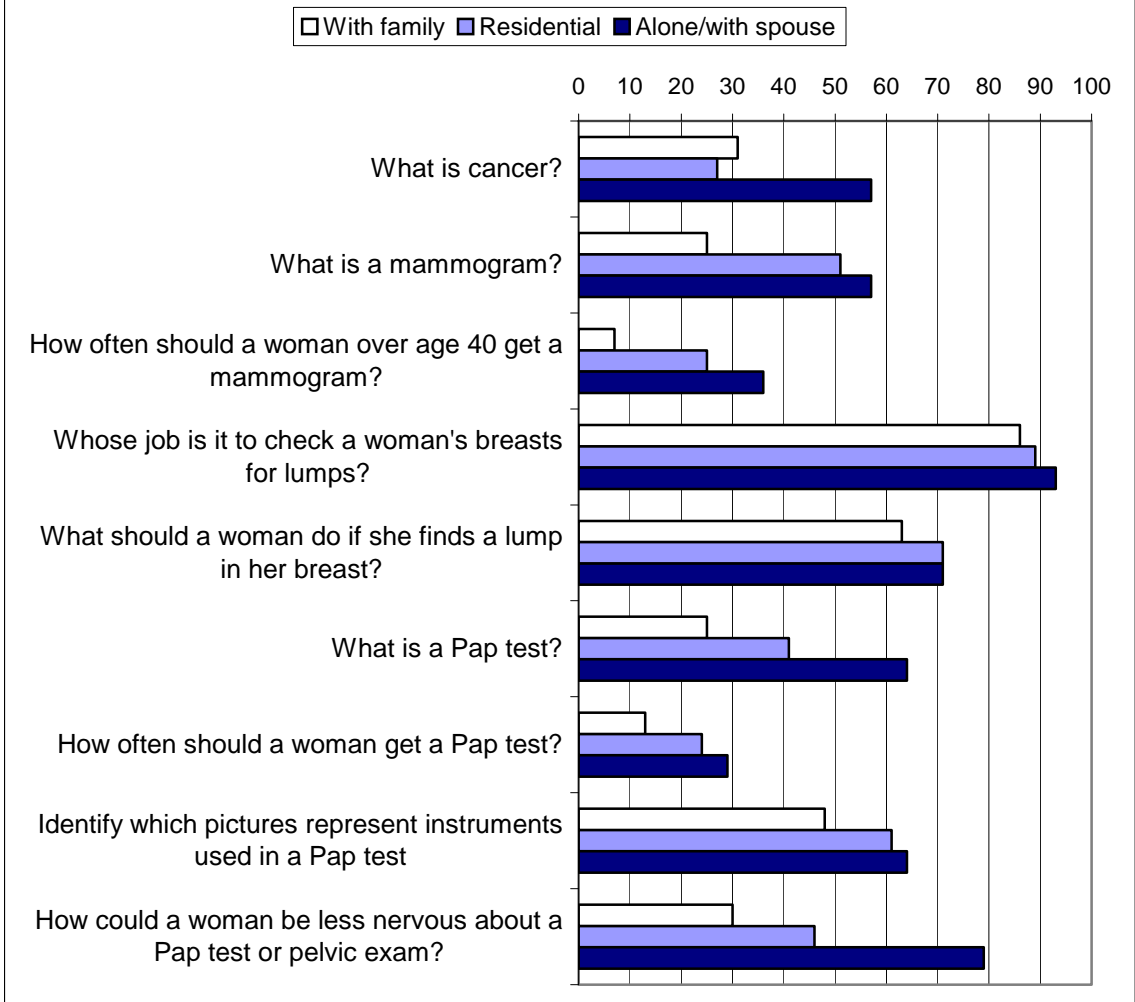
As health care policy and practice increasingly require patients to advocate for their own care, patients’ knowledge about health care and preventive screening becomes increasingly important. Yet women with developmental disabilities lack basic information about standard breast and cervical cancer screenings that are recommended for all women.

Health care providers, service providers, and policymakers can help increase awareness of preventive health:

- Health care providers must provide preventive care to women with developmental disabilities in accordance with standards on recommended care for all women.
- Service providers should offer programming and activities to teach women with disabilities about the importance of cervical and breast cancer screenings, strategies for reducing anxiety associated with these procedures, and approaches for becoming partners in their own health care. All outreach materials should be appropriate for an audience that may have low literacy and cognitive limitations. Women should be given the opportunity to build on the knowledge they have and to help each other learn, such as through a peer training or peer support system.
- To reduce confusion, policymakers should prioritize improving the clarity and consistency of clinical guidelines related to screening procedures and their frequency.

Further research should examine why women who live with family caregivers have less information about preventive health than women living alone, with a spouse, or in a residential setting. Service providers should target outreach to women living with family caregivers and should try to engage families on efforts to improve preventive care.

**Percentage of Women with Developmental Disabilities Correctly Answering Questions about Cervical & Breast Cancer Screening, by Living Situation**



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