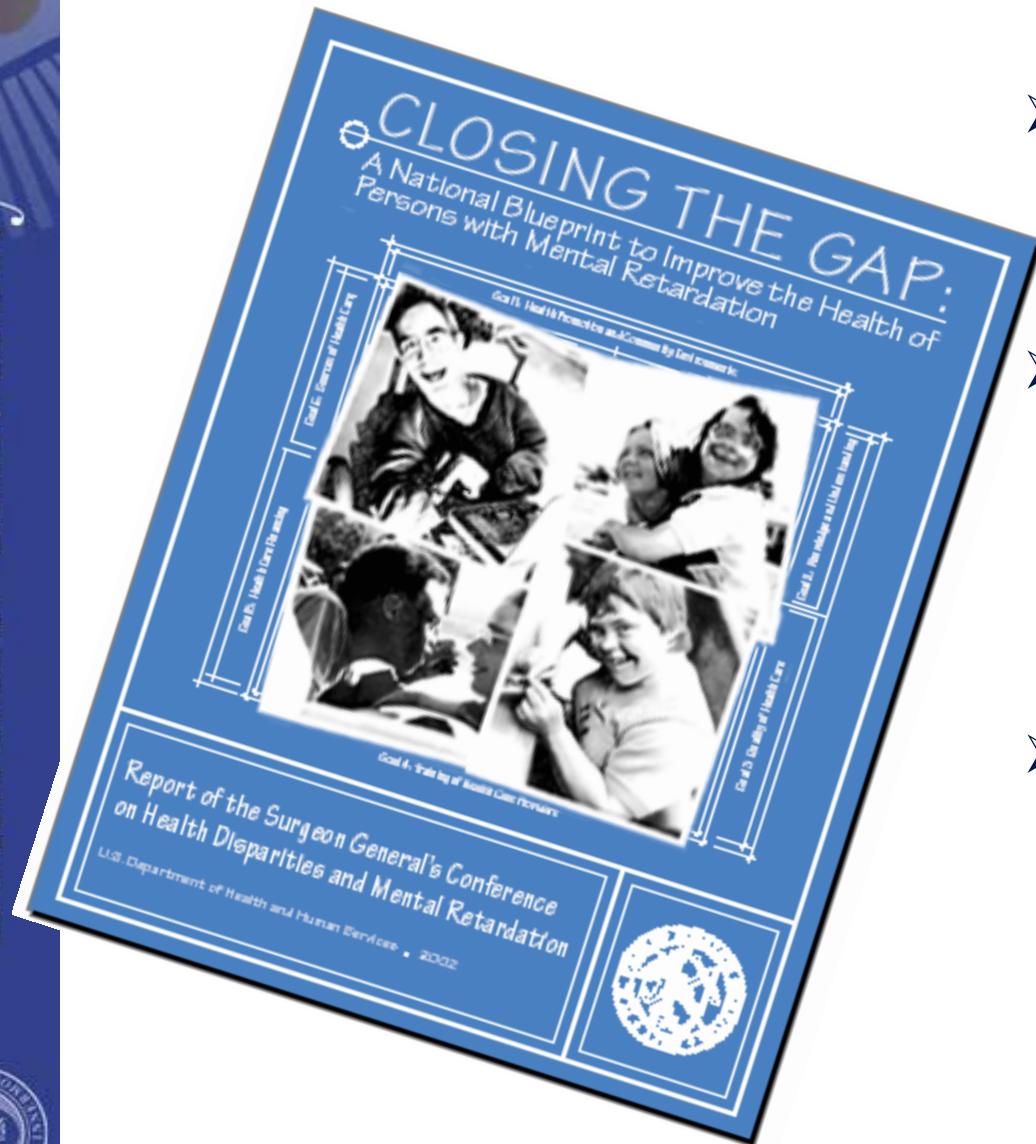


***Access to Cervical and Breast
Cancer Screening for Women with
Developmental Disabilities***

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Context



- “Cascade of disparities” for people with developmental disabilities (Krahn *et al.*)
- Emerging evidence: Health promotion for people with disabilities is critical yet often ignored (Rimmer *et al.*)
- Established commitments to self-determination for people with disabilities
 - little evidence of implementation in health care

Background: Cervical & Breast Cancer Screening

- Cancer screening recommendations set by the US Preventive Health Services Task Force
- Cervical cancer, once the leading cause of cancer deaths among women, is now completely treatable and preventable with Papanicolaou smear test (Pap test)
- Breast cancer: 2nd most frequently diagnosed cancer & 2nd leading cause of cancer deaths in women
- Routine mammography reduces mortality by ~20%
- Changing guidelines
 - Mammography guidelines changed in late 2009 (controversial)
 - Pap test guidelines changed in spring 2013

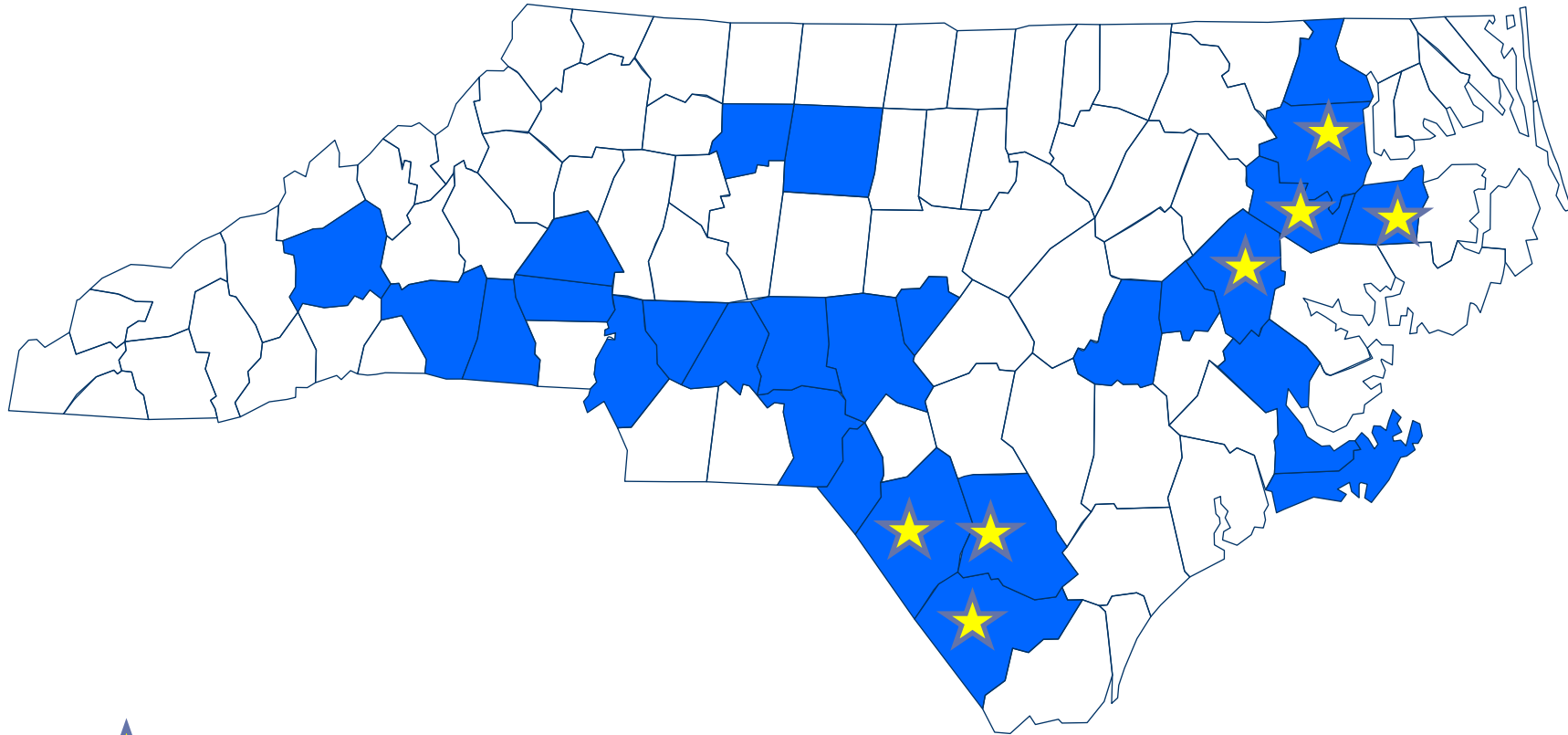
Background: Cervical & Breast Cancer Screening for U.S. Women with DD

- Existing research suggests women with developmental disabilities have among the worst rates of cervical and breast cancer screening in the United States
 - Limitations: Self-reported or proxy-reported data
- Barriers to care
 - Women's limited knowledge
 - Fear surrounding procedures
 - Physicians' pejorative attitudes
- No evidence-based interventions have been established as effective in increasing women's receipt of screening
- Our focus: Empowering women to be informed, assertive patients

Goal 1: Identify cervical & breast cancer screening determinants & rates

- Existing estimates of screening rates derived from self-reported or proxy-reported interview data
 - Biased reporting is highly likely by all women regardless of their disability status
 - Accuracy is unclear: women more accurate about *if* they received screening versus *when* they received screening
 - Accuracy of reporting by women with developmental disabilities has not been studied
- Obtained screening data from medical practices
 - Extraction forms: dates of Pap test, mammography, clinical breast exam, physical exam, insurance type
 - 91% response rate from 253 medical practices
 - Item non-response 6-9% for each procedure in last year

Participants' counties of residence

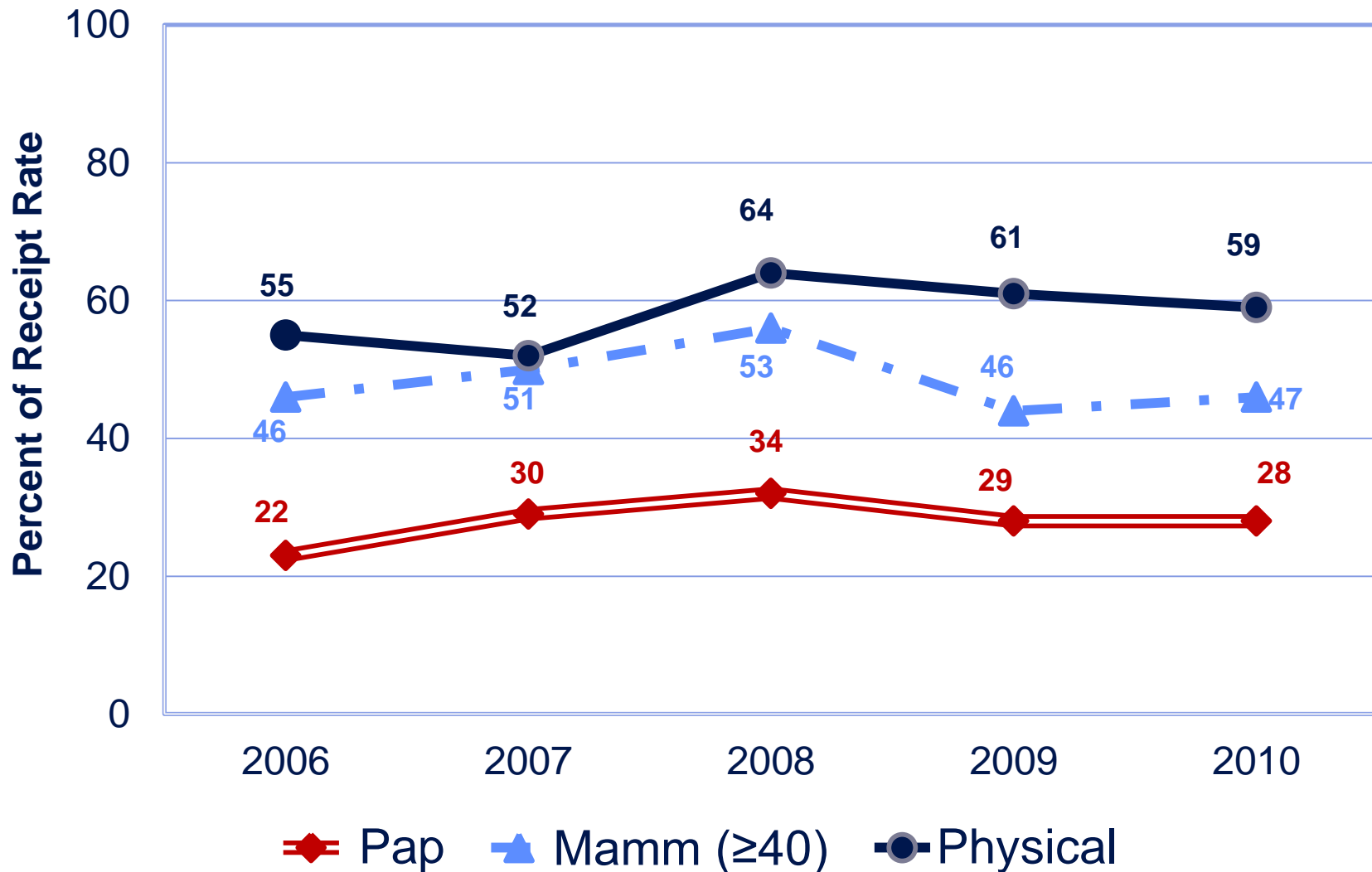


★ = Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor

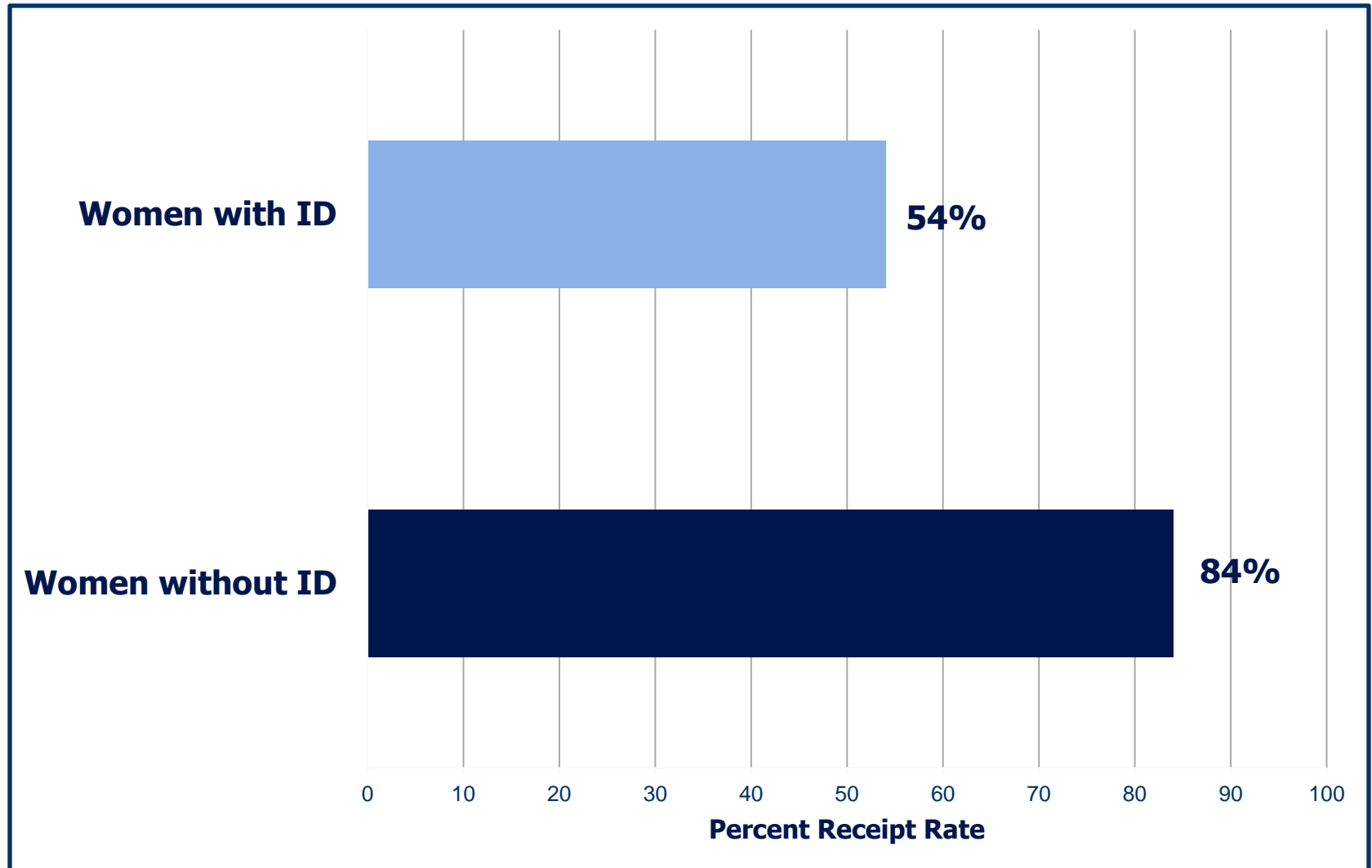
Description of the Sample

Characteristic	n = 203 women
Race is Black	47%
Race is Asian, Native or Latina	3%
Has a child	13%
Lives alone or with partner	8%
Lives in formal residential setting	40%
Lives with family caregiver	45%
Age (mean)	40 years (19 - 71 years range)
Impairment is mild or moderate	91%
Lives in rural area	75%
Insured	>99%

Percent of women receiving screening procedures, 2006-10



Pap test receipt among NC women ≥ 18 in 2008, 2009, or 2010



* North Carolina data from 2010 BRFSS

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Determinants of Cervical Cancer Screening

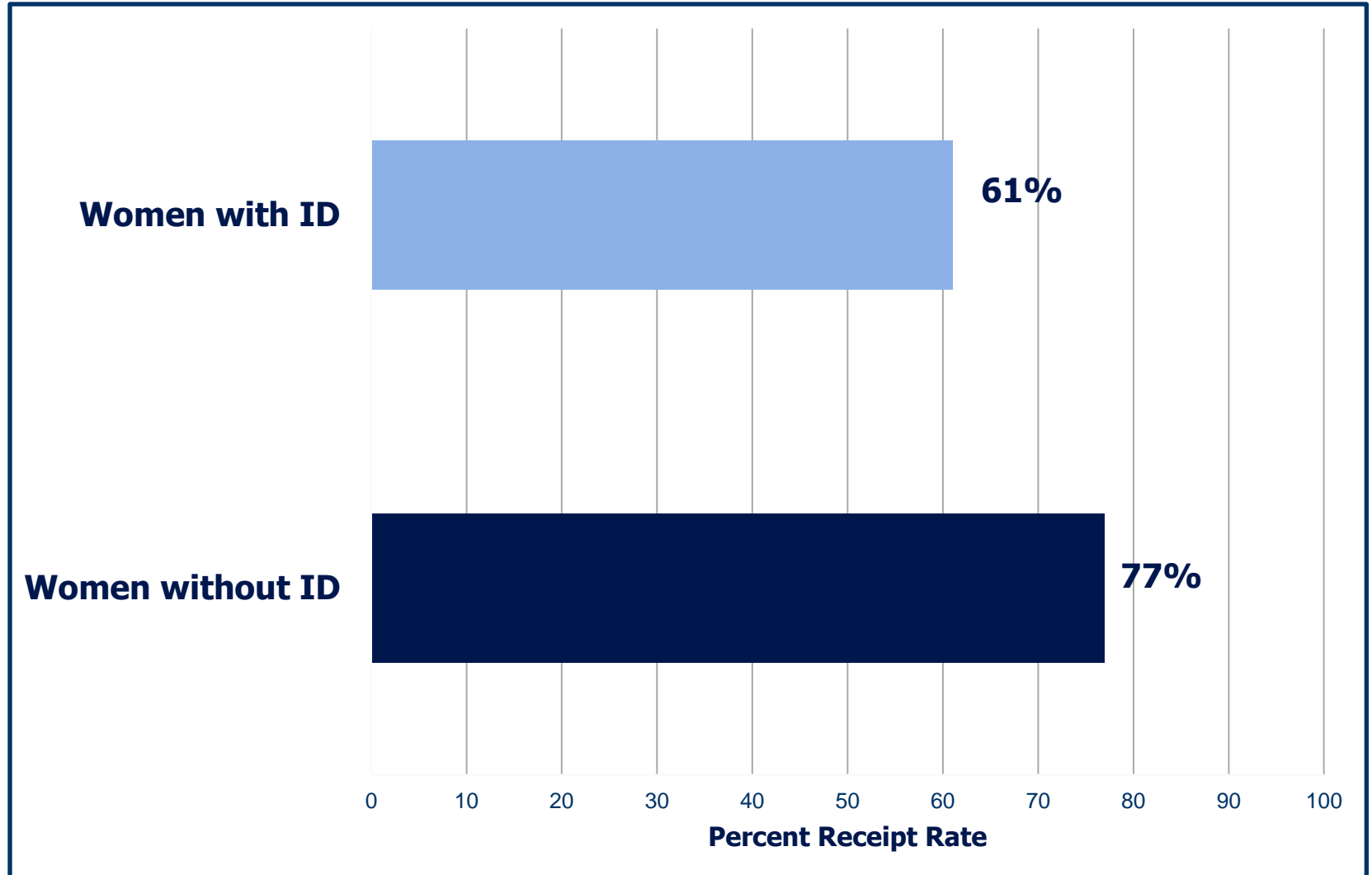
Women were more likely to receive cervical cancer screening if they:

- Lived in a residential facility (as opposed to at home with family caregiver)
- Lived in a rural area
- Received care from an OB/GYN

Parish et al (2013) *Public Health Reports*



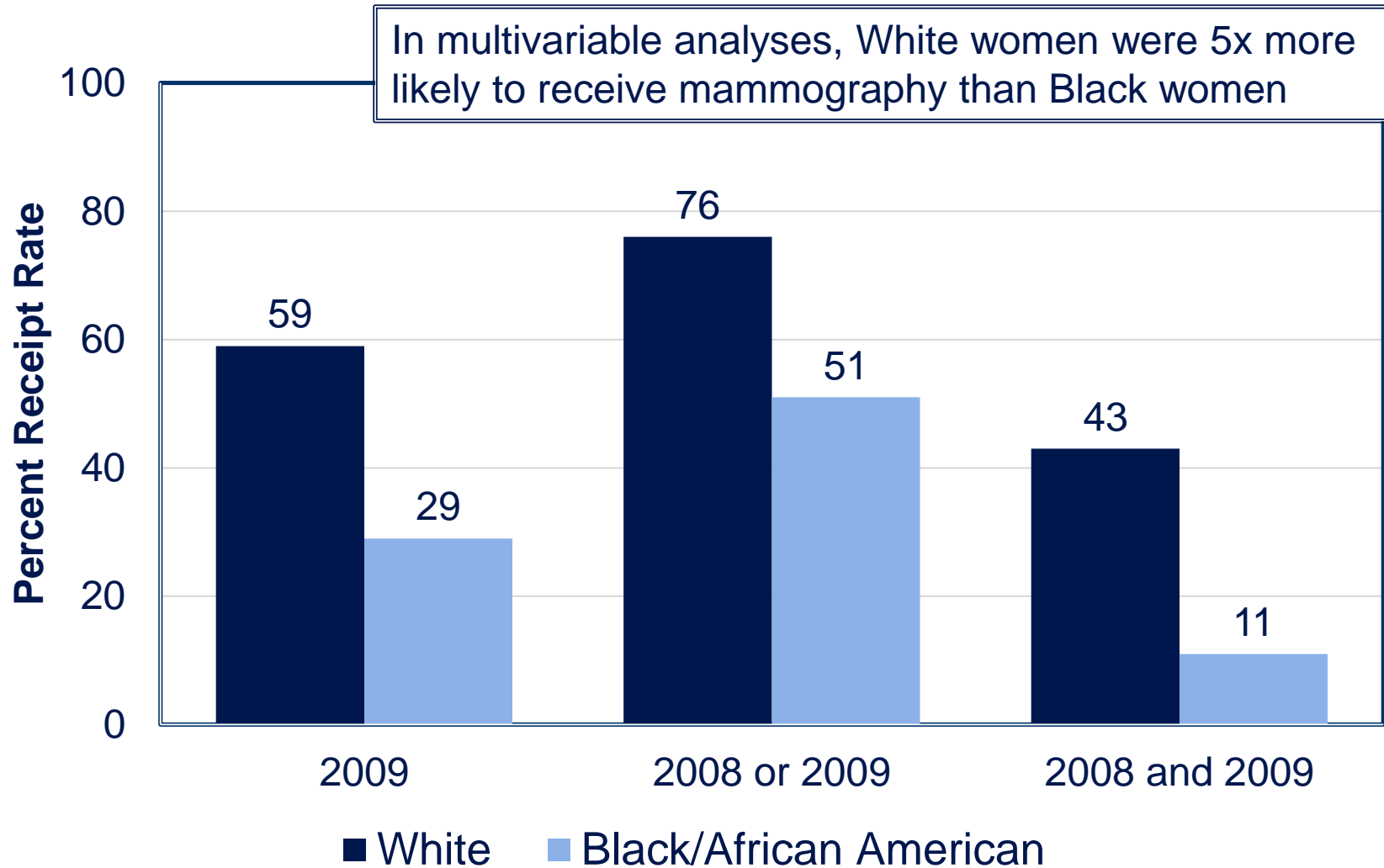
Mammography receipt among NC women ≥ 40 in 2009 or 2010



* North Carolina data from 2010 BRFSS

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Unadjusted mammography rates for Black & White women ages ≥ 40



Goal 2: Develop and test revised intervention to promote cervical and breast cancer screening

- *Women Be Healthy 2*
- Expansion of *Women Be Healthy* developed by Lunsky, Straiko, Armstrong; (revised by Haverkamp, Dickens)
 - In randomized control trial, *Women Be Healthy 1 improved* breast cancer screening knowledge of women with intellectual disabilities but not cervical cancer screening knowledge
- 3 focus groups with women with ID and 15 instructor interviews
 - Women particularly uncomfortable with content related to cervical cancer

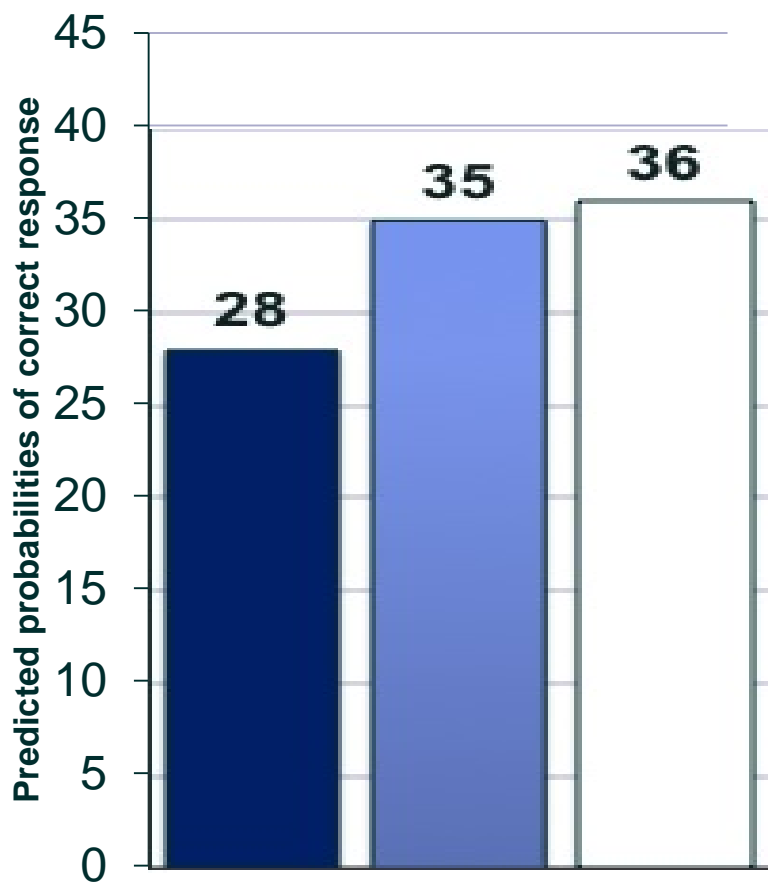
Women Be Healthy 2

- WBH2 is 22-session (1 hour twice/weekly) psychoeducational program for women with intellectual and developmental disabilities
- Content: anatomy, cancer, importance of screenings, how to communicate with health care provider, relaxation, field trip to GYN office & mammography site, multimedia, hands-on activities
- All activities geared for learners without literacy
- Doubled content on pelvic exams, cervical cancer & screenings from 3 to 6 hours
- Expanded relaxation activities
- Curriculum is **FREE** and available on the Lurie Institute for Disability Policy website:
<http://lurie.brandeis.edu/women/curriculum.html>

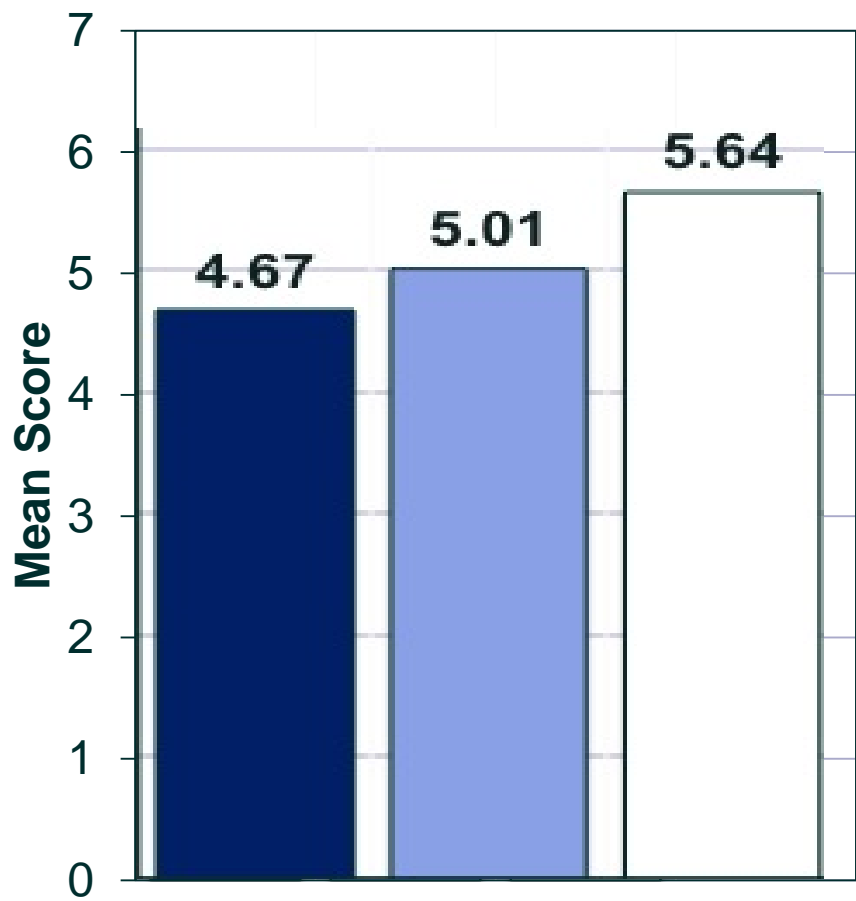
Goal 3: Test *Women Be Healthy 2*

- Randomized control trial
- 21 sites across North Carolina
 - Community rehab programs
 - Community colleges
 - Other disability service provider organizations
- Pre-test, post-test interview design
 - Computer-assisted, in-person interviews
- Randomized sample at each site
- Curriculum taught by on-site instructors (not research team members)
- Compared WBH1, WBH2 to women in the control group
- 9 indicators of knowledge plus composite

Post-test Knowledge of Women with I/DD



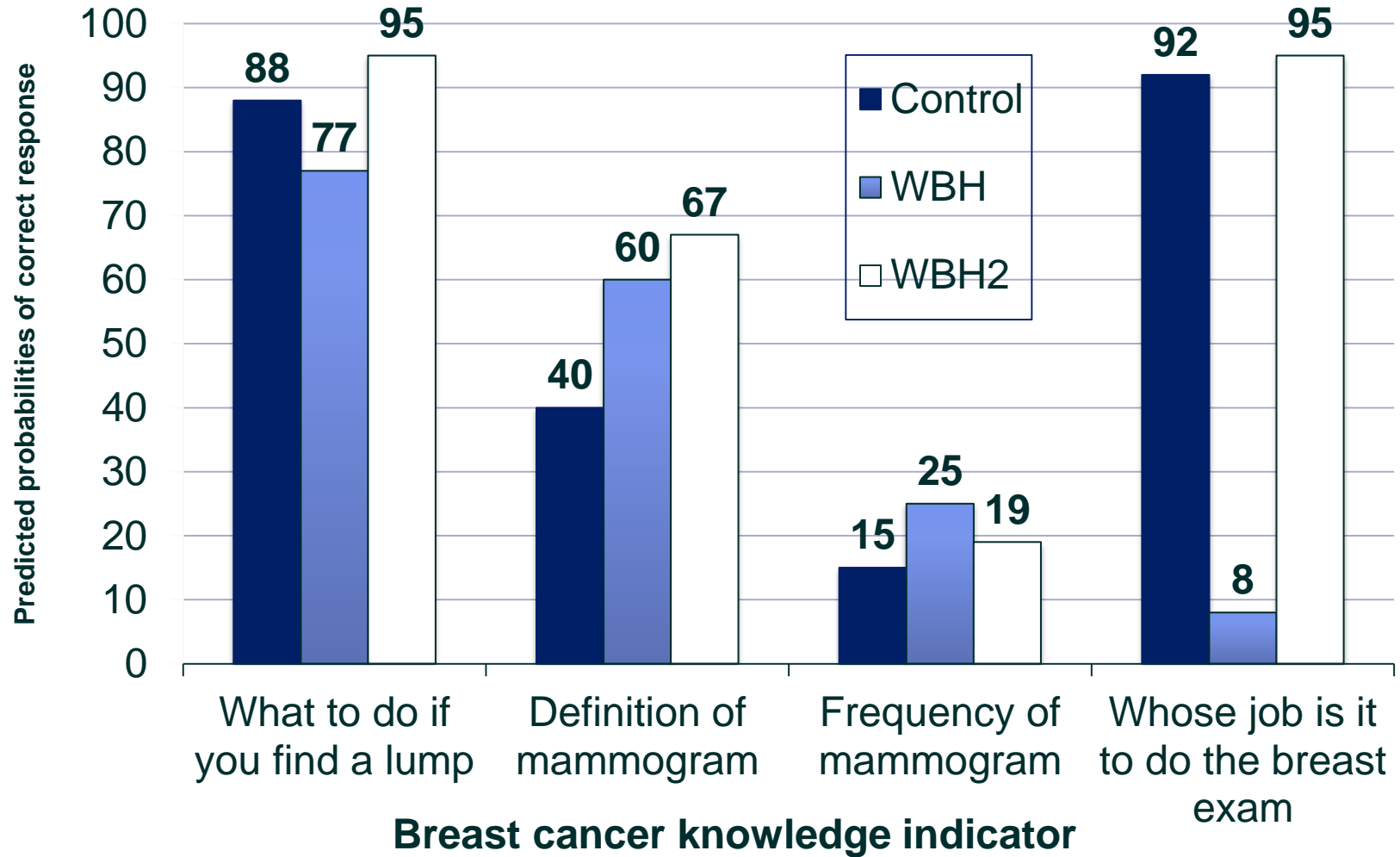
Definition of cancer



9 item composite

Note: adjusted for baseline, living arrangement & site type

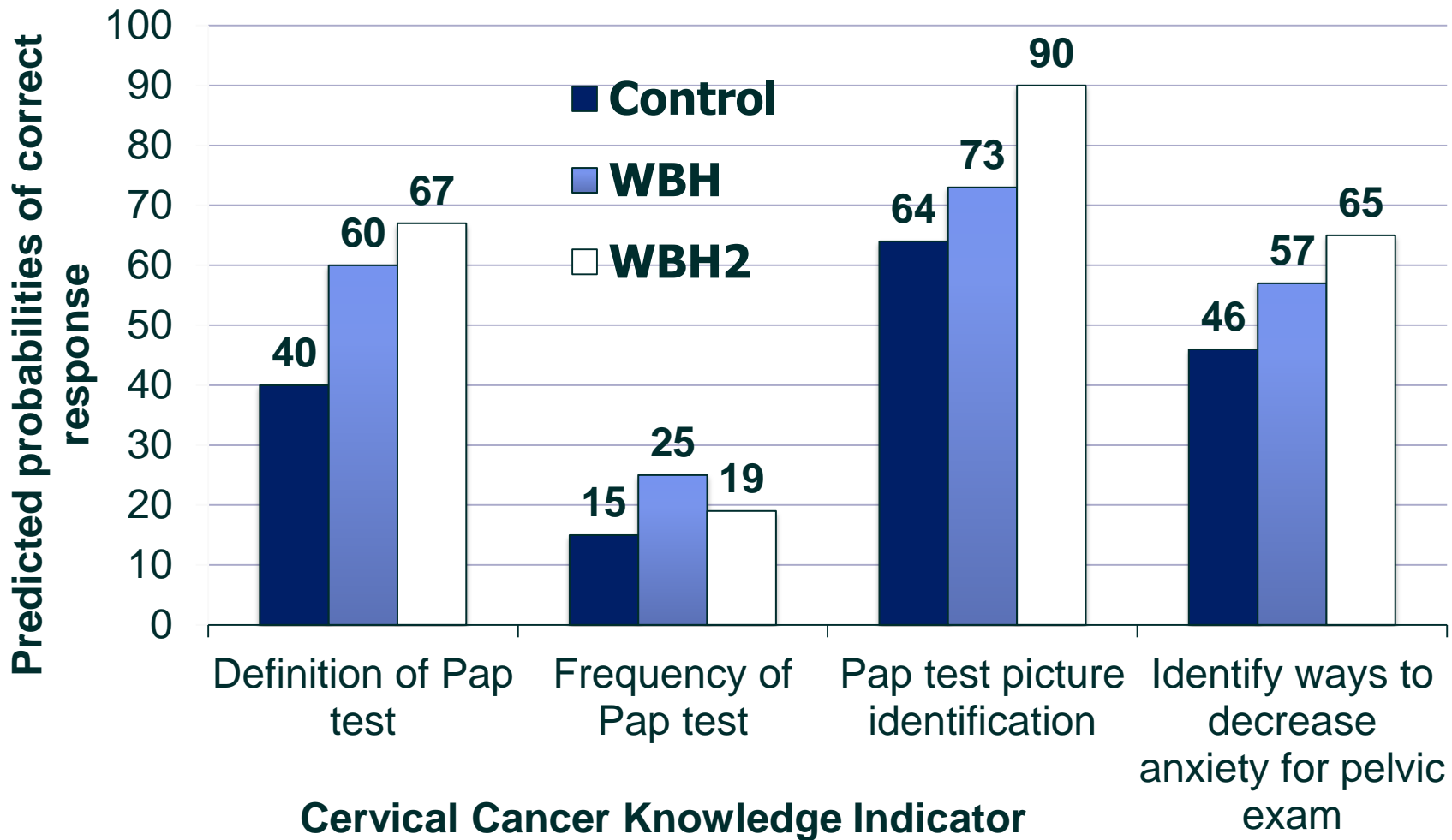
Predicted Probabilities: Post-test Breast Cancer Knowledge



Note: adjusted for baseline, living arrangement & site type



Post-test Cervical Cancer Knowledge of Women with I/DD



Note: adjusted for baseline, living arrangement & site type



Implications

- Women with developmental disabilities have low rates of cervical and breast cancer screening
- Women with developmental disabilities who live in the community have limited knowledge about cervical and breast cancer screening
- A targeted intervention, geared to learners with low literacy, can improve the knowledge about cervical and breast cancer screening of women with developmental disabilities
- Modest knowledge gains in breast cancer but not cervical cancer indicate greater duration of content related to cervical cancer is necessary
- Clear need for targeted intervention with women, caregivers, health care providers

Some Important Anecdotes

- Some women with ID were raped, sometimes by multiple perpetrators
- Some women had children (13% of the sample), sometimes with multiple partners
- Some women had HIV or HPV
- Many women were sexually active
- Many women were using birth control
- Several medical providers stated that the women did not need Pap tests because of their ID
- Two physicians wrote on medical record forms “not needed because mentally retarded” *[sic]*

Conclusions

- Women with intellectual and developmental disabilities do not receive cervical and breast cancer screening according to clinical guidelines
- Assertive efforts are needed to ensure that Black women with intellectual and developmental disabilities receive mammography
- Women with intellectual and developmental disabilities can benefit from a tailored intervention to improve their knowledge about these screenings
- *Women with ID who live in the community are at risk for developing HPV and cervical cancer and should receive Pap tests according to clinical guidelines*

Check us out on YouTube!

<http://www.youtube.com/watch?v=jgTrbWUdclg>

Thank you!

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For more info:

<http://lurie.brandeis.edu/women/index.html>