

***Cervical and Breast Cancer Screening
of Women with Intellectual Disabilities:
Evidence of Inadequate Receipt***

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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 2009 (controversial)
 - Pap test guidelines changed ~1 month ago

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

- Existing research suggests women with intellectual and 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
- Women with intellectual disabilities have both protective and risk factors for cervical and breast cancer

Determine Cervical & Breast Cancer Screening Rates

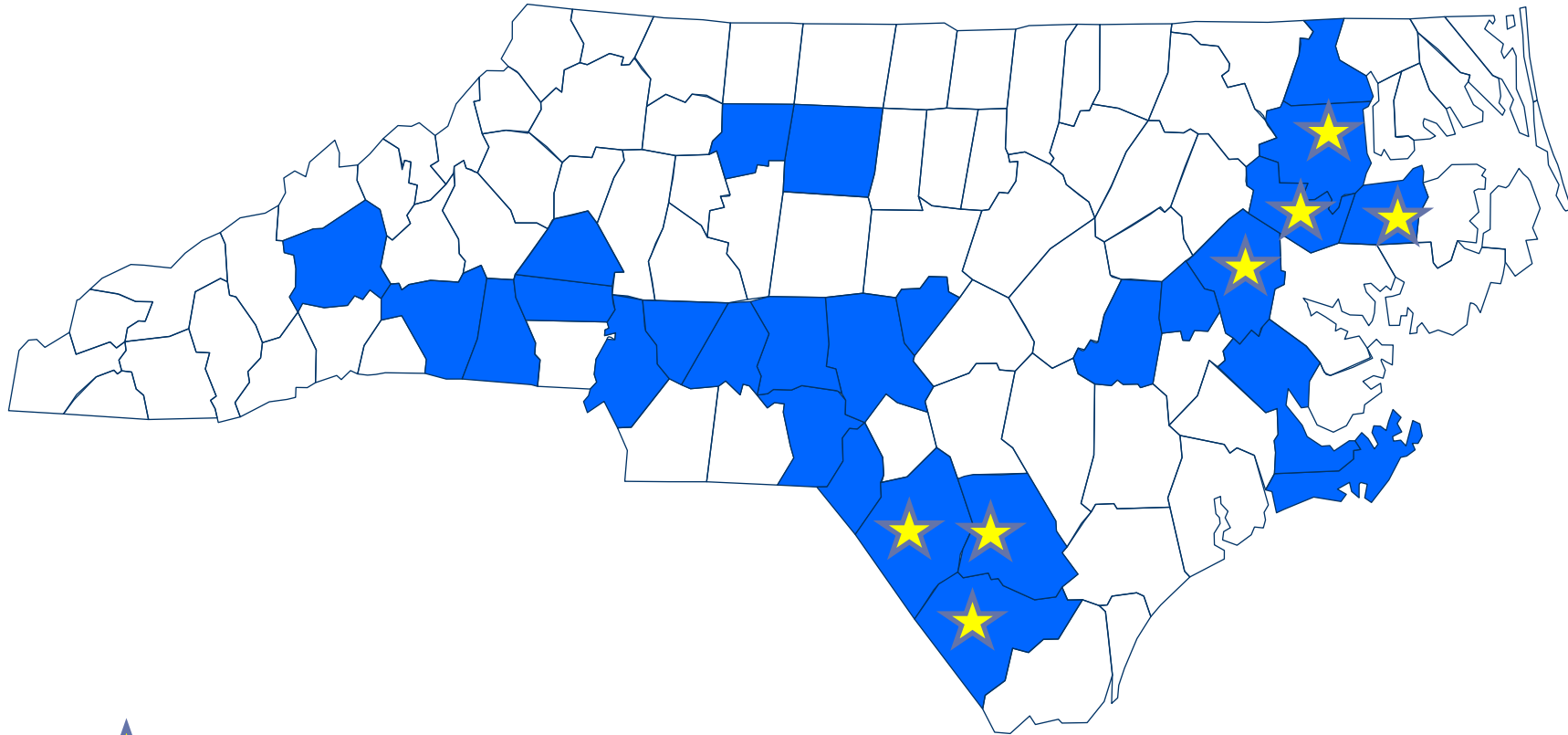
- Existing estimates of screening rates derived from self-reported or proxy-reported interview data
 - Biased reporting is highly likely by all women regardless of their disability status
 - Accuracy is unclear: women more accurate about whether they received screening than when they received screening
 - Accuracy of reporting by women with intellectual 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 analyzed

Description of the Sample

Characteristic	n = 202 women
Race is Black	47%
Race is Asian, Native or Latina	3%
Has a child	13%
Lives alone or with partner	8%
Lives in paid/formal residential setting	46%
Lives with family caregiver	46%
Age (mean)	41 years (19 - 71 years range)
Impairment is mild or moderate	91%
Lives in rural area	75%
Insured	>99%

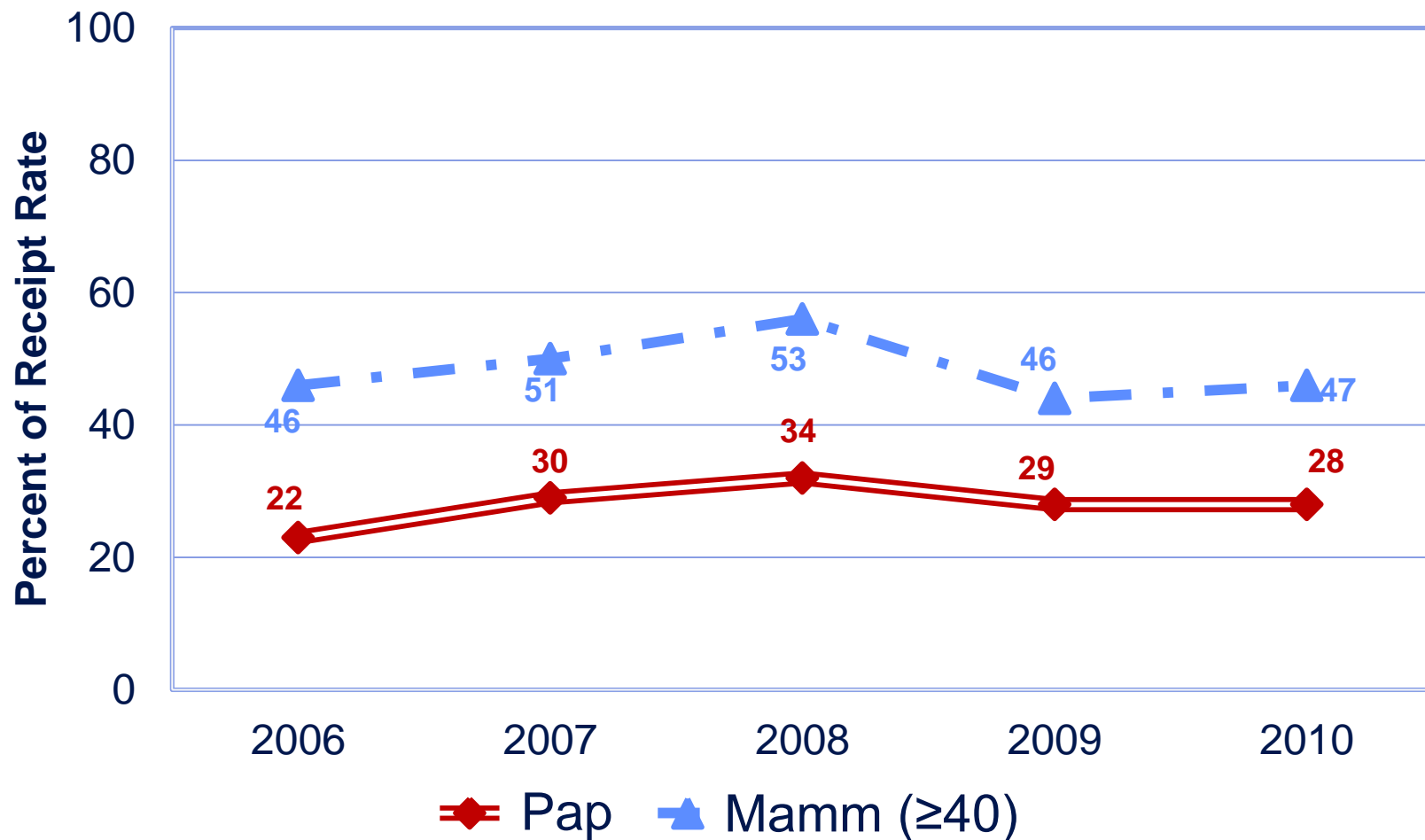


Participants' counties of residence

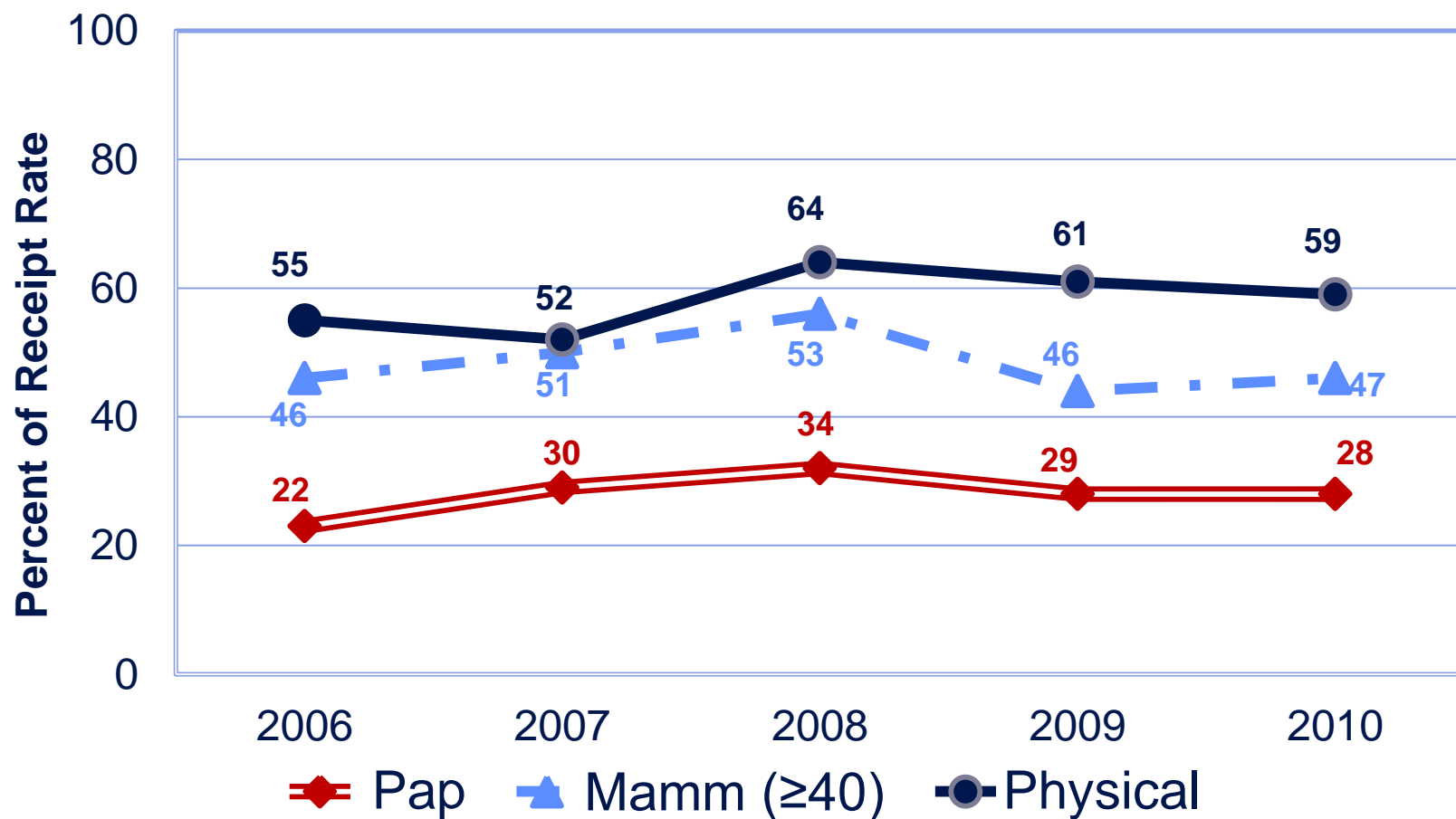


★ = Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor

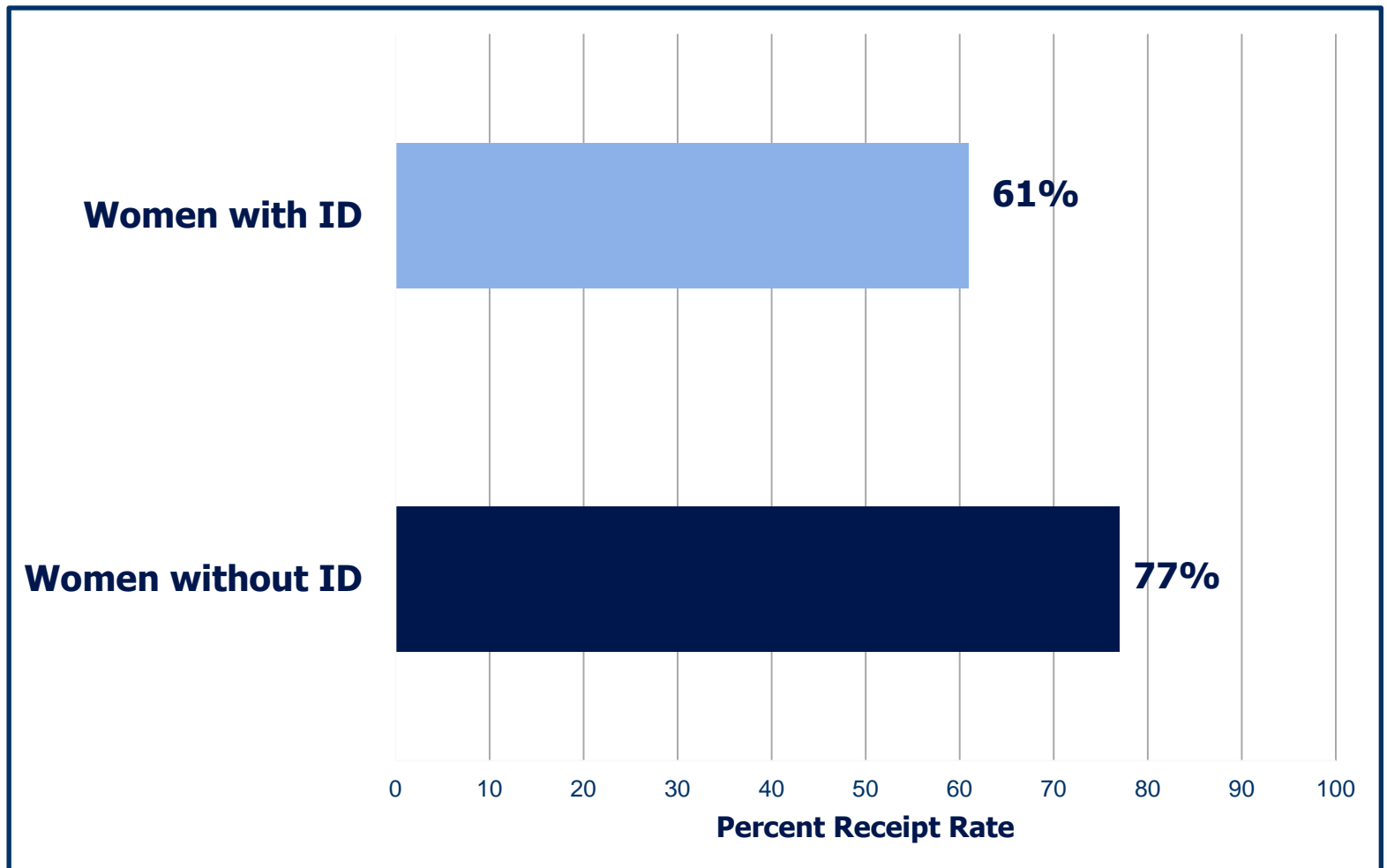
Percent of women with ID receiving screening procedures, 2006-10



Percent of women with ID receiving screening procedures, 2006-10



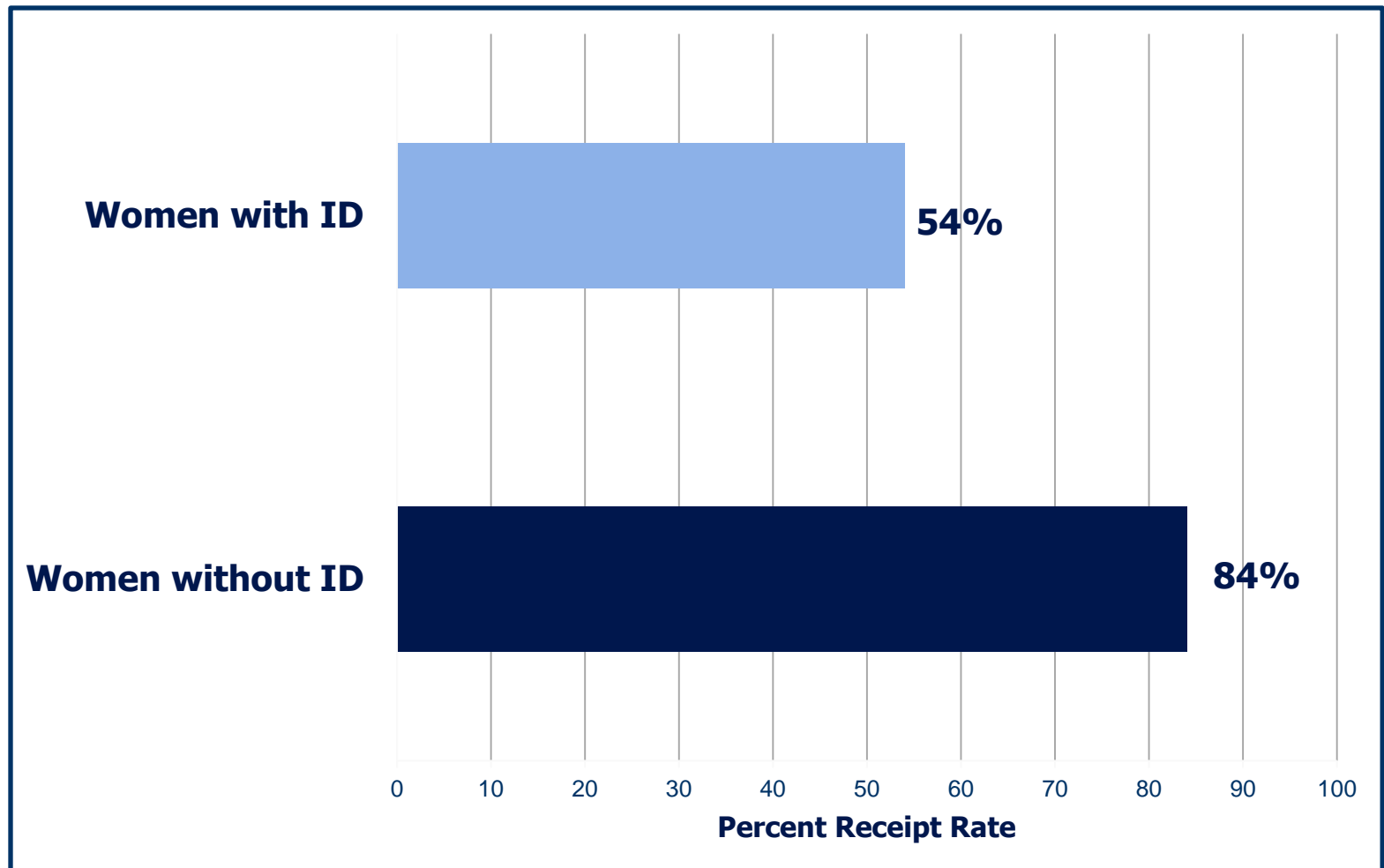
Mammography receipt among NC women ≥ 40 in 2009 or 2010



* North Carolina data from 2010 BRFSS

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



* North Carolina data from 2010 BRFSS

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Some Noteworthy Anecdotes

- Women with intellectual disabilities were often raped and/or had children, sometimes by multiple partners
 - Increased risk for cervical cancer
- Some medical providers stated that the women did not need Pap tests because of their impairments
 - Two wrote on medical record forms “not needed because mentally retarded” (*sic*)

Conclusions

- Women with intellectual disabilities have exceptionally low rates of cervical and breast cancer screening
- Clear need for targeted intervention with women, caregivers, health care providers

Thank you!

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For more info:

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