

***Cervical Cancer Screening for
Women with Intellectual
Disabilities***

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for ONCODEFI

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

- Existing research suggests women with intellectual disabilities have among the worst rates of cervical and breast cancer screening in the United States
- We found 72% reduced likelihood of Pap test receipt for women with cognitive disabilities compared to other US women (Parish & Saville 2006)
- Lewis et al (2002) found 39% of women with ID received Pap tests in California in 1997
- Limitations: Self-reported or proxy-reported data

Aim: Identify objective cervical cancer screening rates & determinants

- Existing estimates of screening rates derived from self-reported or proxy-reported interview data
 - Biased reporting is highly likely by all women
 - Accuracy is unclear: women more accurate about *if* they received screening versus *when* they received screening
 - Women with intellectual disabilities lack understanding of the exam and may be unable to accurately report receipt
 - Caregivers may lack knowledge about the woman's medical care

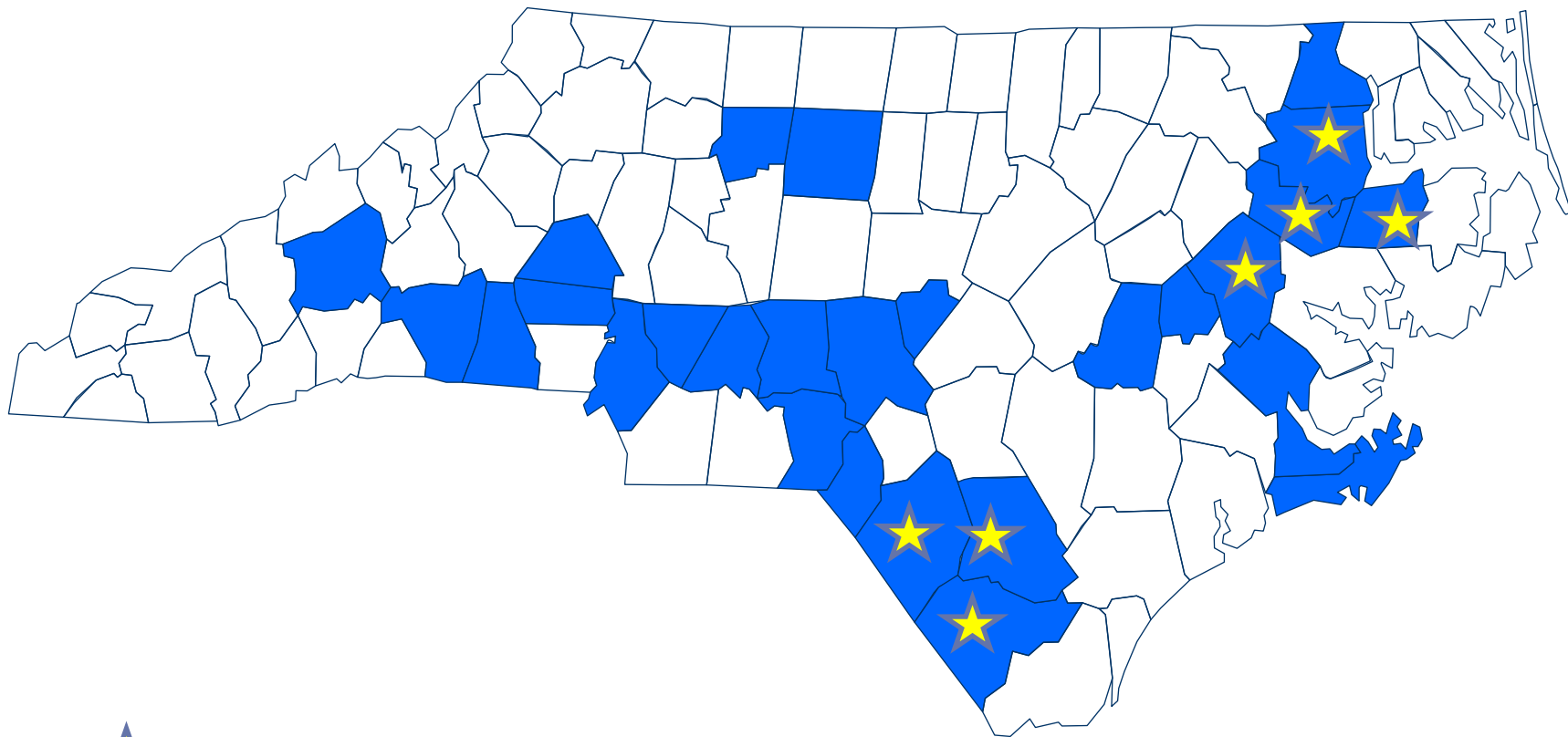
Procedure

- Physicians and medical practices obtained from the women, their staff, and/or family caregivers
- Obtained screening data from medical practices
 - Abstraction forms sought dates of Pap test, mammography, clinical breast exam, physical exam, insurance type for each year from 2006-10
 - 91% response rate from 253 medical practices
 - Item non-response 6-9% for each procedure in last year
 - 1-10 faxed requests needed to obtain records
- Some facilities sent women's entire medical records and not just the abstraction form
- Women (and guardians, as needed) previously provided informed consent and HIPAA consent

Description of the Sample

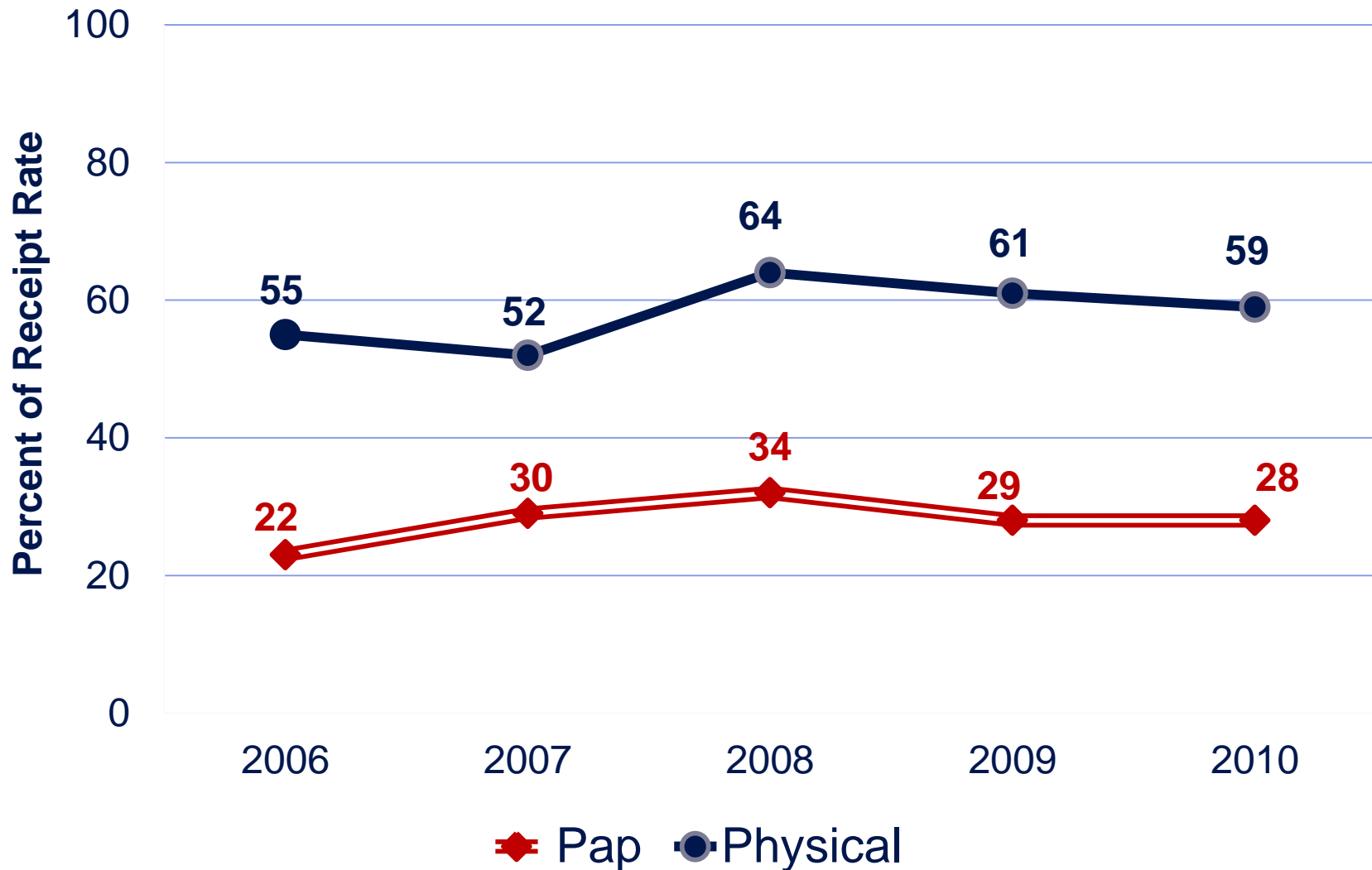
Characteristic	n = 163 women
Race is Black	43%
Race is Asian, Native or Latina	3%
Has a child	14%
Lives alone or with partner	8%
Lives in formal residential setting	51%
Lives with family caregiver	41%
Age (mean)	40 years (19 – 65 range)
Impairment is mild or moderate	92%
Lives in rural area	74%
Insured	>99% (94% public)
Has legal guardian	36%
Unable to correctly define Pap test	64%
Someone accompanies woman into examination room	65%

Participants' counties of residence in North Carolina, US

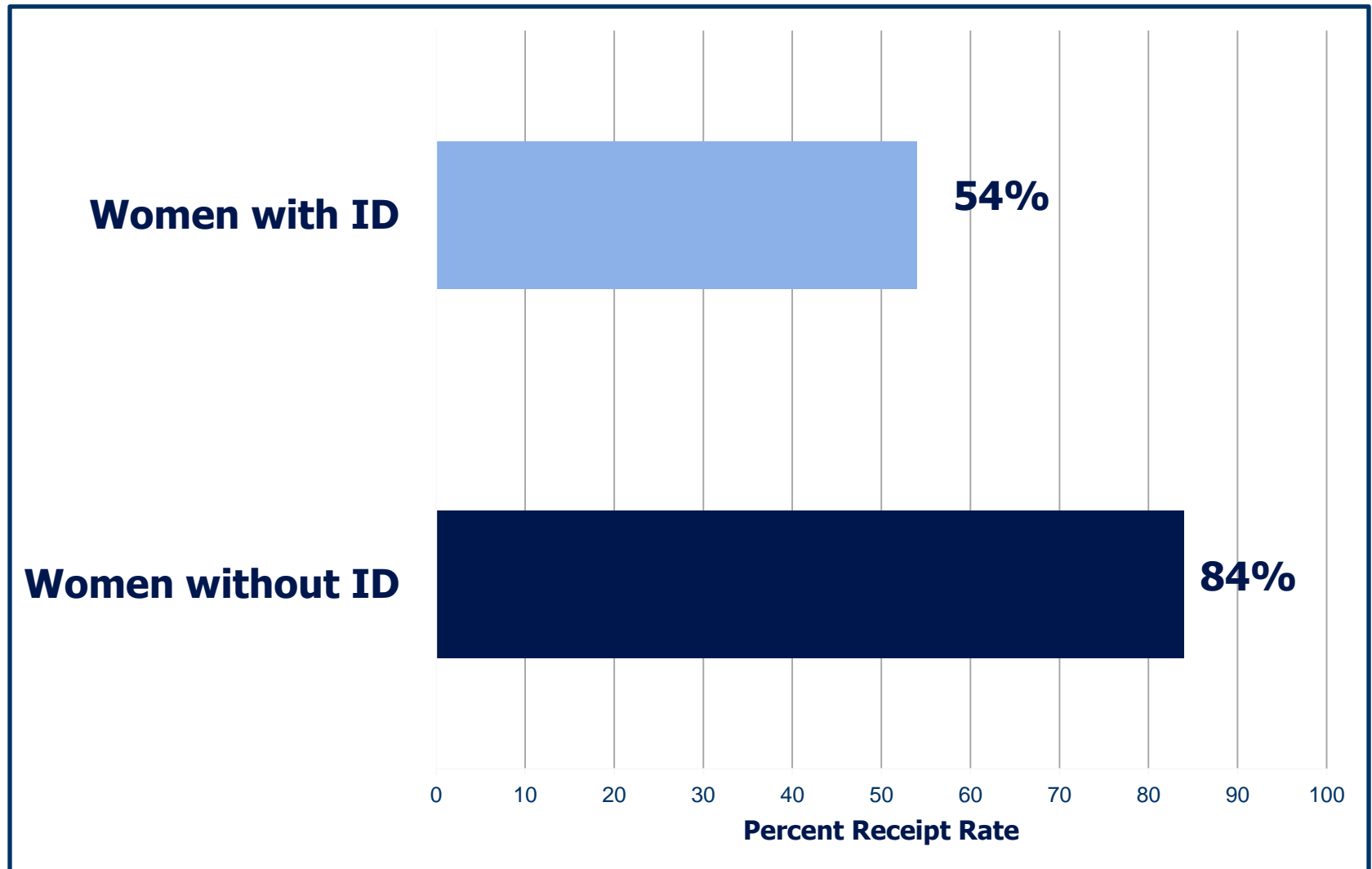


★ = Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor

Percent of women 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 (odds ratio [OR] =1.79 compared to those living with family caregiver)
- Lived in a rural area (OR = 3.43 compared to those living in urban settings)
- Received care from an Obstetrician/Gynecologist (OR =1.87 compared to those receiving care from generalist)
- **Not** associated with receipt of Pap: race, age, guardianship status, someone accompanies into exam room, impairment severity, knowledge of Pap test, insurance type, history of childbearing

Parish et al (2013) *Public Health Reports*

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Some Important Anecdotes

- Some women 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 intellectual disabilities
- Two physicians wrote on medical record forms “not needed because mentally retarded” [*sic*]

Do women with intellectual disabilities *need* cervical cancer screening?

- An estimated 68-83% of women with intellectual disabilities assaulted during lifetime, compared to 18% of nondisabled women (Tyiska; Tjaden & Thoennes)
- Women are unlikely to report their sexual histories to health care providers in the presence of a paid or family caregiver
 - Caregivers are often the perpetrators of sexual assault, making reporting to health care providers even less likely
- Women lack knowledge about sexually transmitted diseases and often about anatomy
- Women's fear of exams may lead to inaccurate reporting of sexual history
- **Yes!**

Conclusions

- Women with intellectual disabilities do not receive cervical cancer screening according to clinical guidelines
- Women with intellectual disabilities who live in the community are at risk for developing HPV and cervical cancer and should receive Pap tests according to clinical guidelines

Thank you!

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For more info:

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