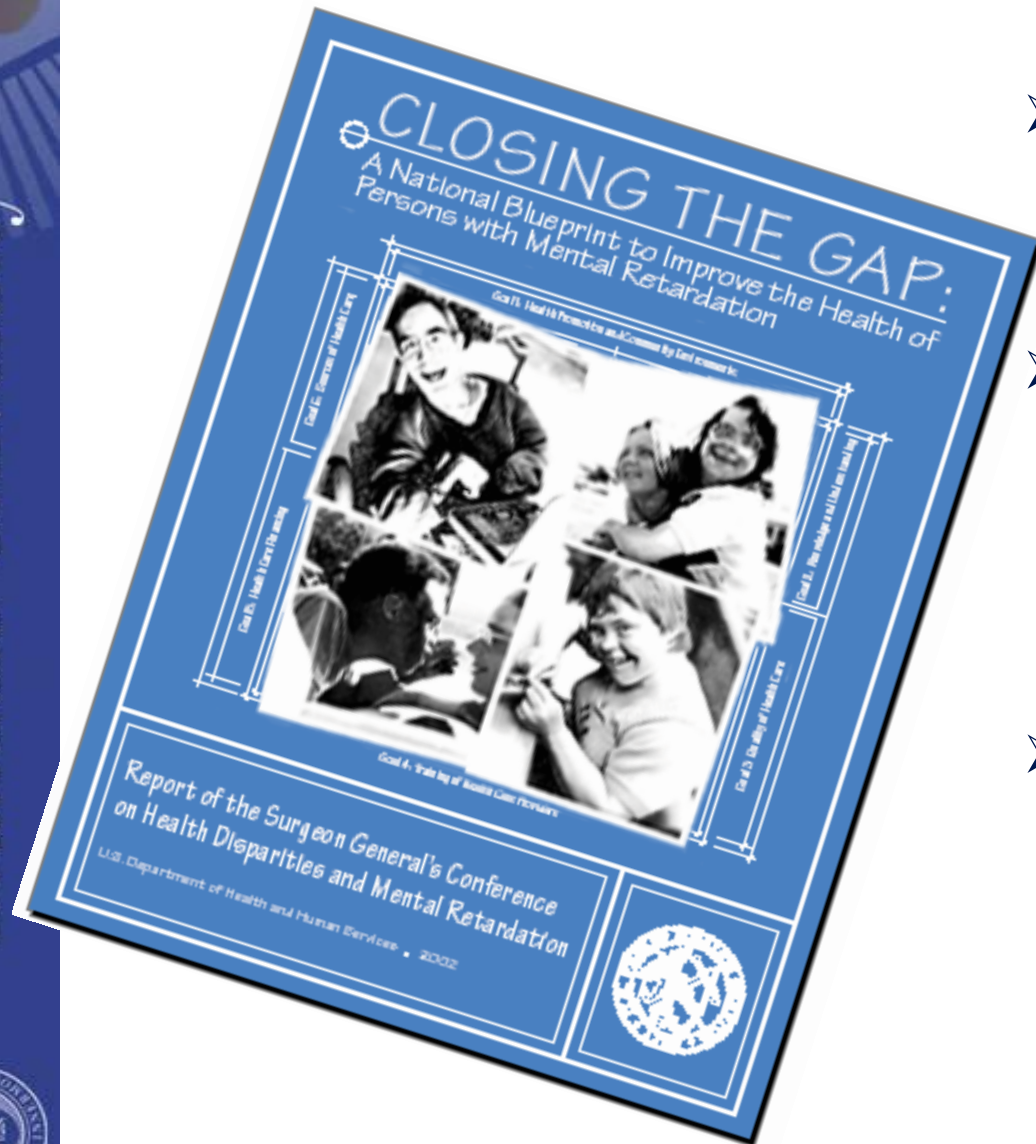


Increasing Cervical and Breast Cancer Screening of Women with Developmental Disabilities

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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 2009 (controversial)
 - Pap test guidelines changed ~3 weeks ago

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

Background: *Women Be Healthy*

- Health promotion intervention designed to empower women with developmental disabilities to obtain cervical and breast cancer screening
- 90-minute psycho-educational classes, once/weekly
 - Eighth week is graduation (7 weeks of instruction)
- Content: anatomy, cancer, importance of screenings, communicating with health care providers, field trip to GYN office
- Preliminary testing: women reported satisfaction
- Developers: Lunsky, Straiko, Armstrong; (revised by Havercamp, Dickens)

NIDRR Field-Initiated Research: Study & Sub-Studies



First Priority: Development of Inclusive Research Protocol

- People with developmental disabilities have historically been research subjects but not research *partners*
- Research team includes a woman with developmental disabilities
- Majority of Advisory Board is women with developmental disabilities
- Partnership: protocol developed collaboratively with women with developmental disabilities, prior to grant development
 - Recruiting procedures
 - Consent procedures
 - Interview procedures
 - Knowledge translation activities
- Extensive training of Advisory Board; commitment to collaboration
- Builds from Heller *et al.*

On the Ground: Recruiting & Consent

- Community partner sites sought across North Carolina
 - Community rehab programs, developmental disability service providers, community colleges
 - Some organizations refused to participate because of the nature of the project (sex ed concerns)
- Concern: how to *ethically* recruit women with developmental disabilities?
 - Guardians can be coercive
 - Agency staff can be coercive
 - Acquiescence is a worry
- Research team (not partner sites) obtained assent/consent because of concerns related to coercion

Recruiting & Consent, 2

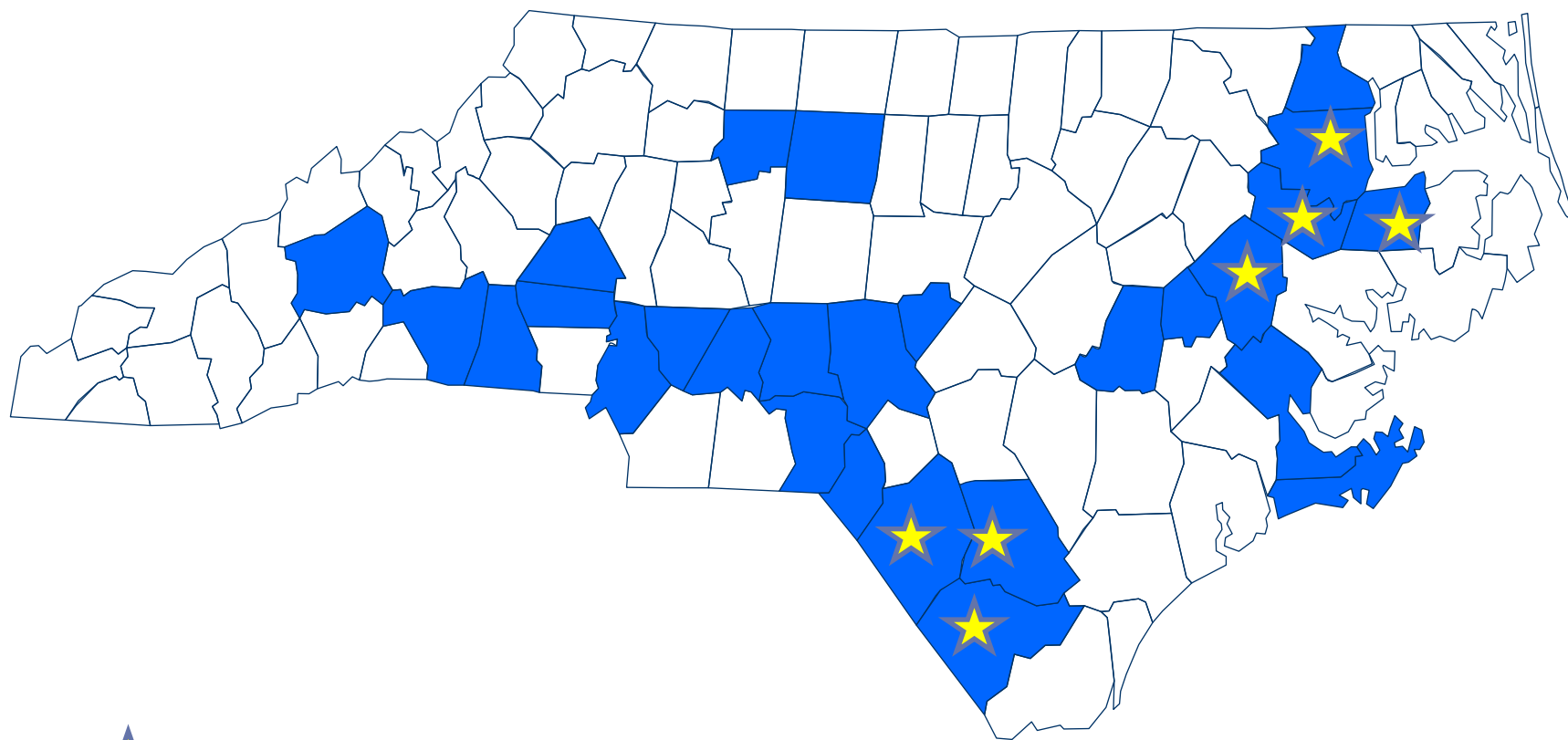
- Information sessions held at partner sites
- Sought assent *first* from women, then sought consent from guardians (if necessary)
- Research team explained WBH and the study
 - Multiple methods: video, written material, pictures, discussion, question & answer sessions, individual talks with women who had questions
 - Parents, staff, guardians invited (some staff attended)
 - HIPAA protections explained & discussed
- Consent process effectively recruited women with developmental disabilities
 - 203 (75%) of 269 women who attended information sessions enrolled in the study
 - 83% of women with guardians & 86% of women without guardians consented; 61% of guardians consented
- Ethical issues remain: women whose guardians did not consent were excluded (per IRB)



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%

Participants' counties of residence

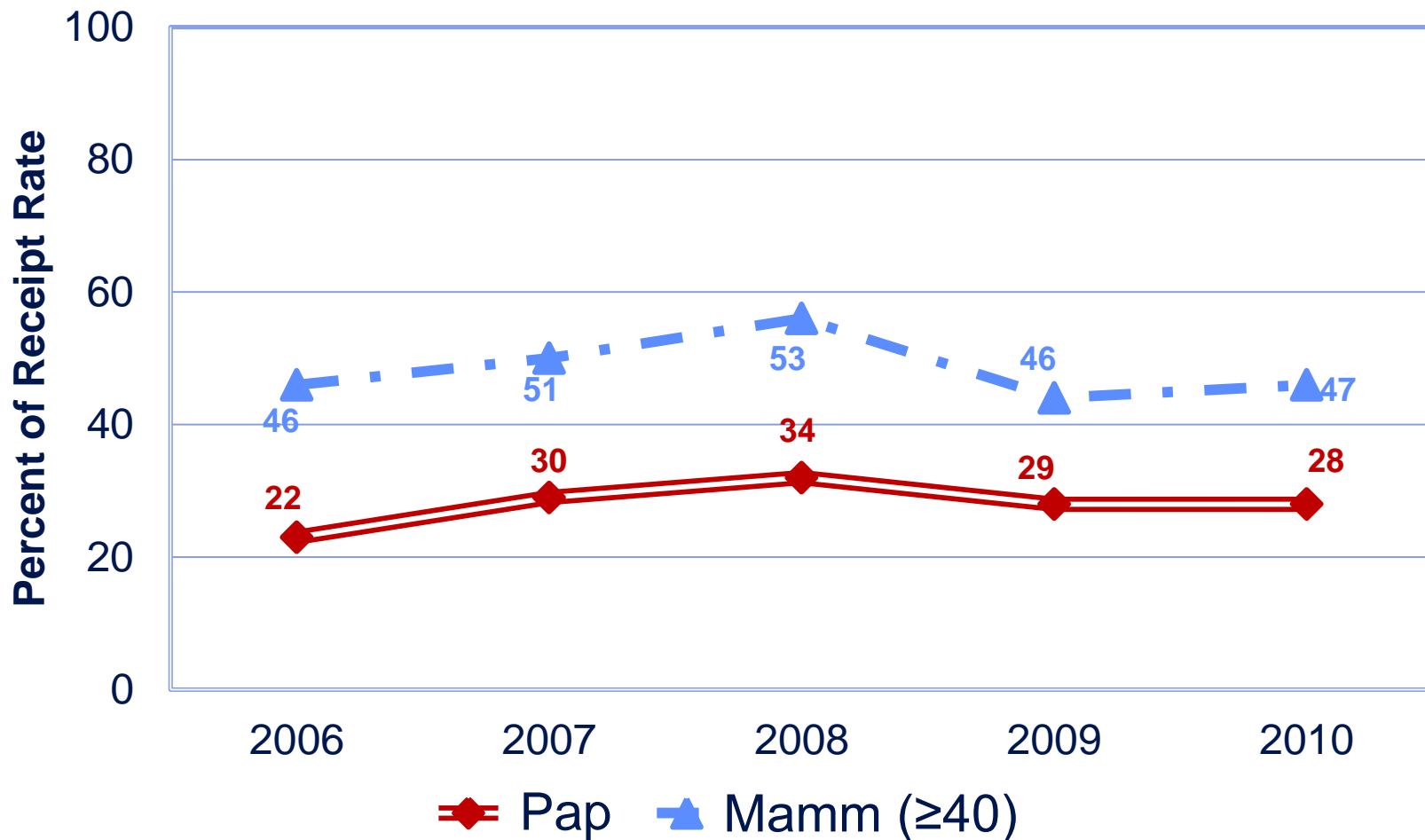


★ = Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor

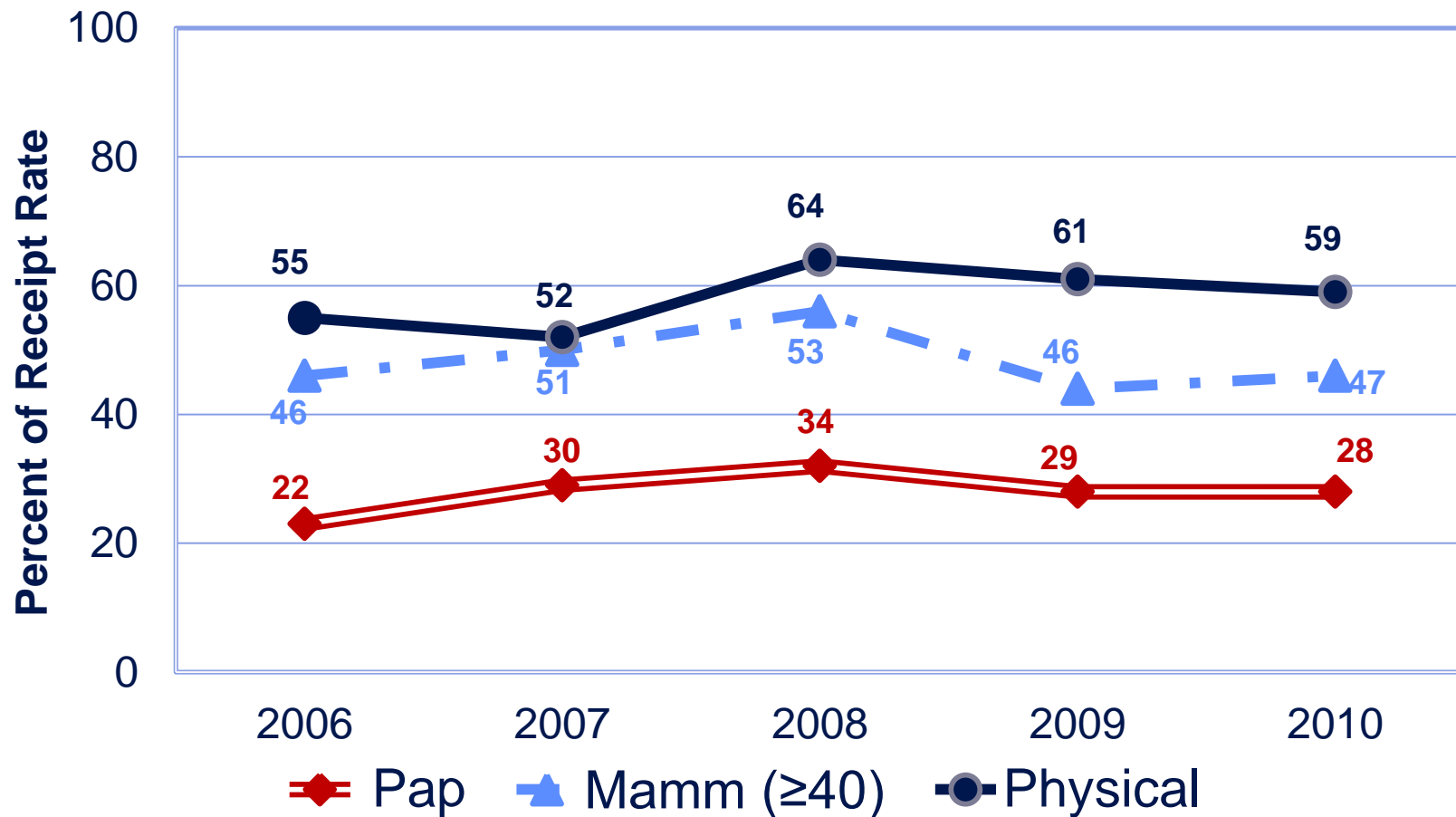
Determine Cervical & Breast Cancer Screening Rates

- 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 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 analyzed

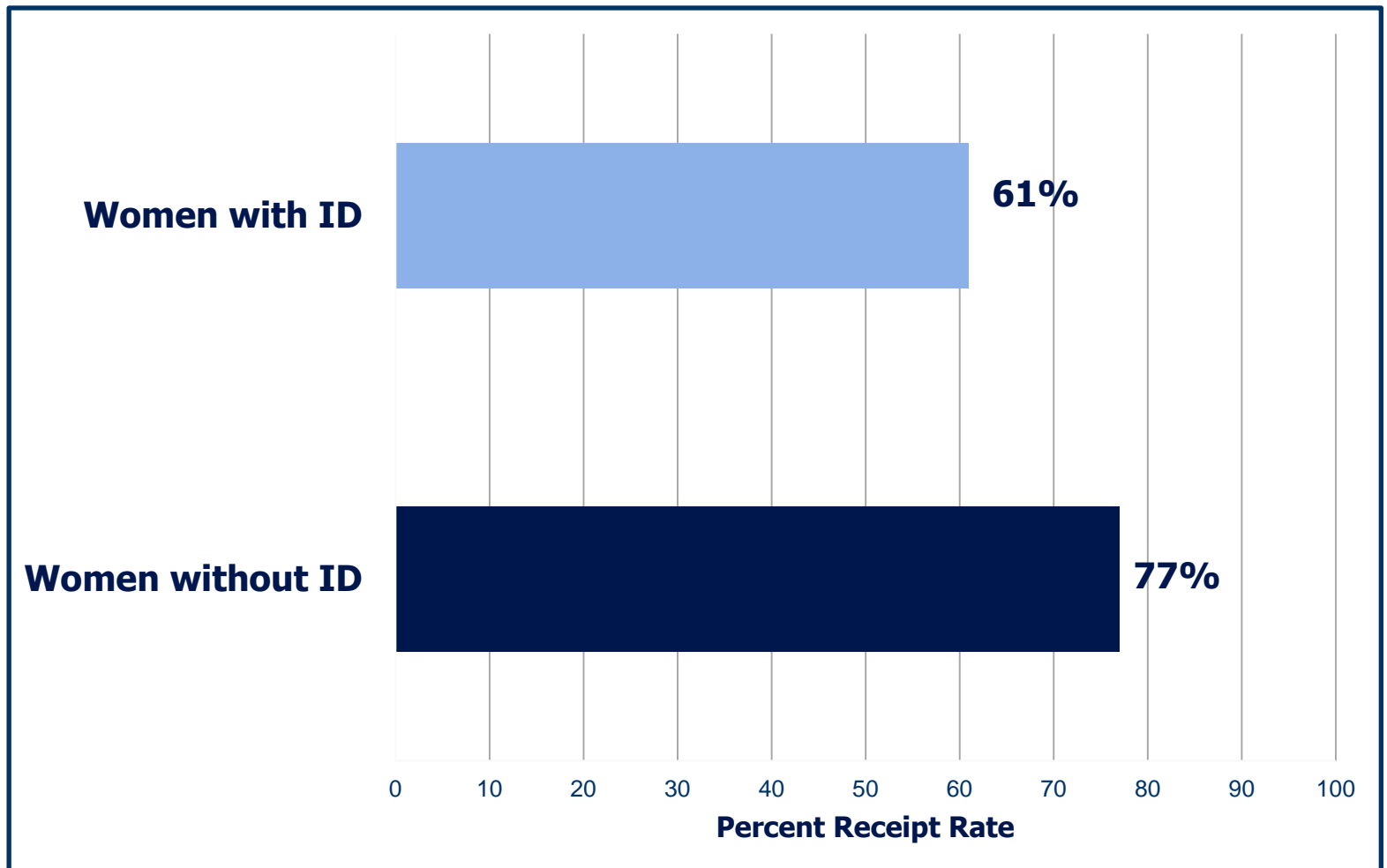
Percent of women receiving screening procedures, 2006-10



Percent of women receiving screening procedures, 2006-10



Mammography receipt among NC women ≥ 40 in 2009 or 2010

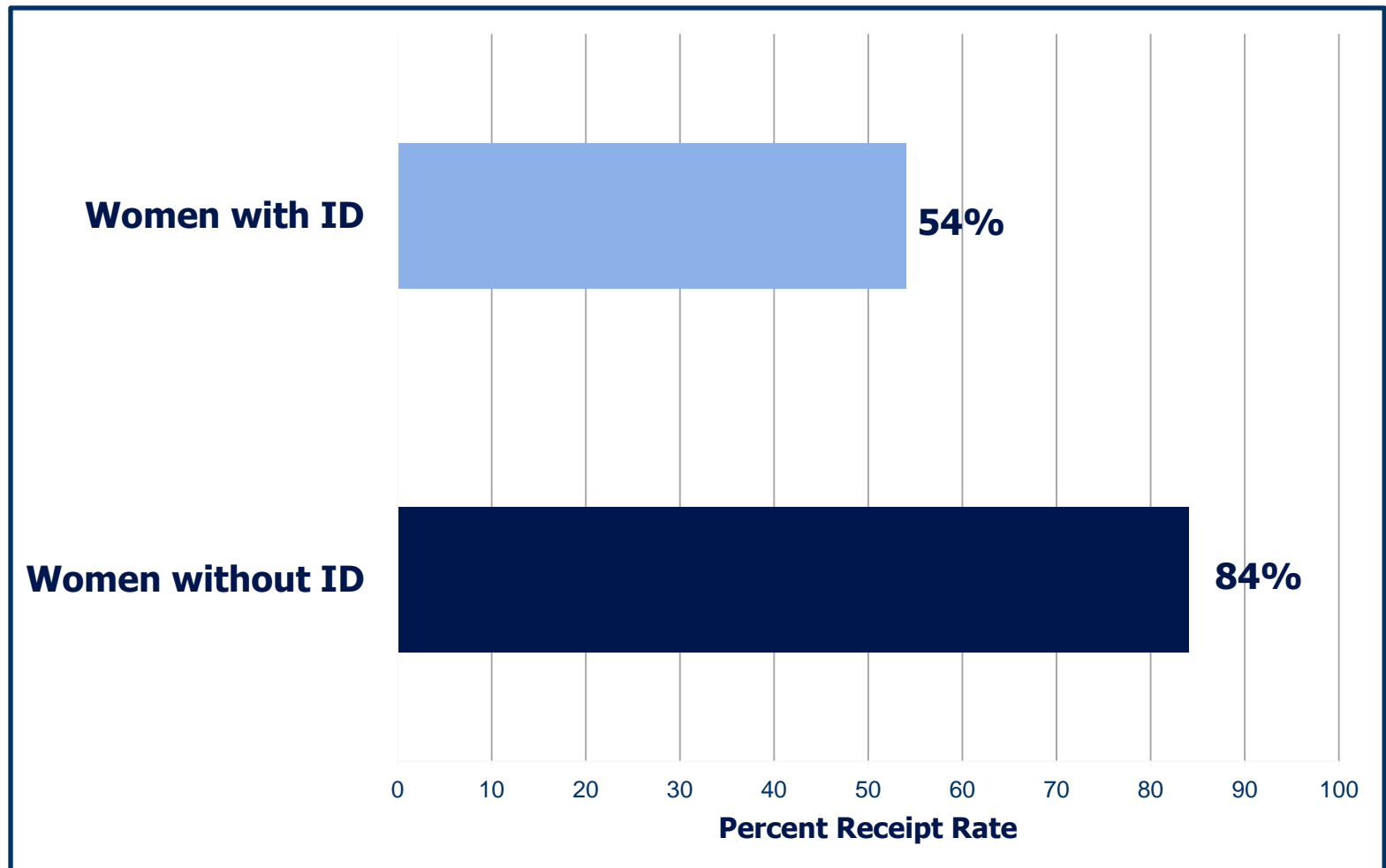


* North Carolina data from 2010 BRFSS

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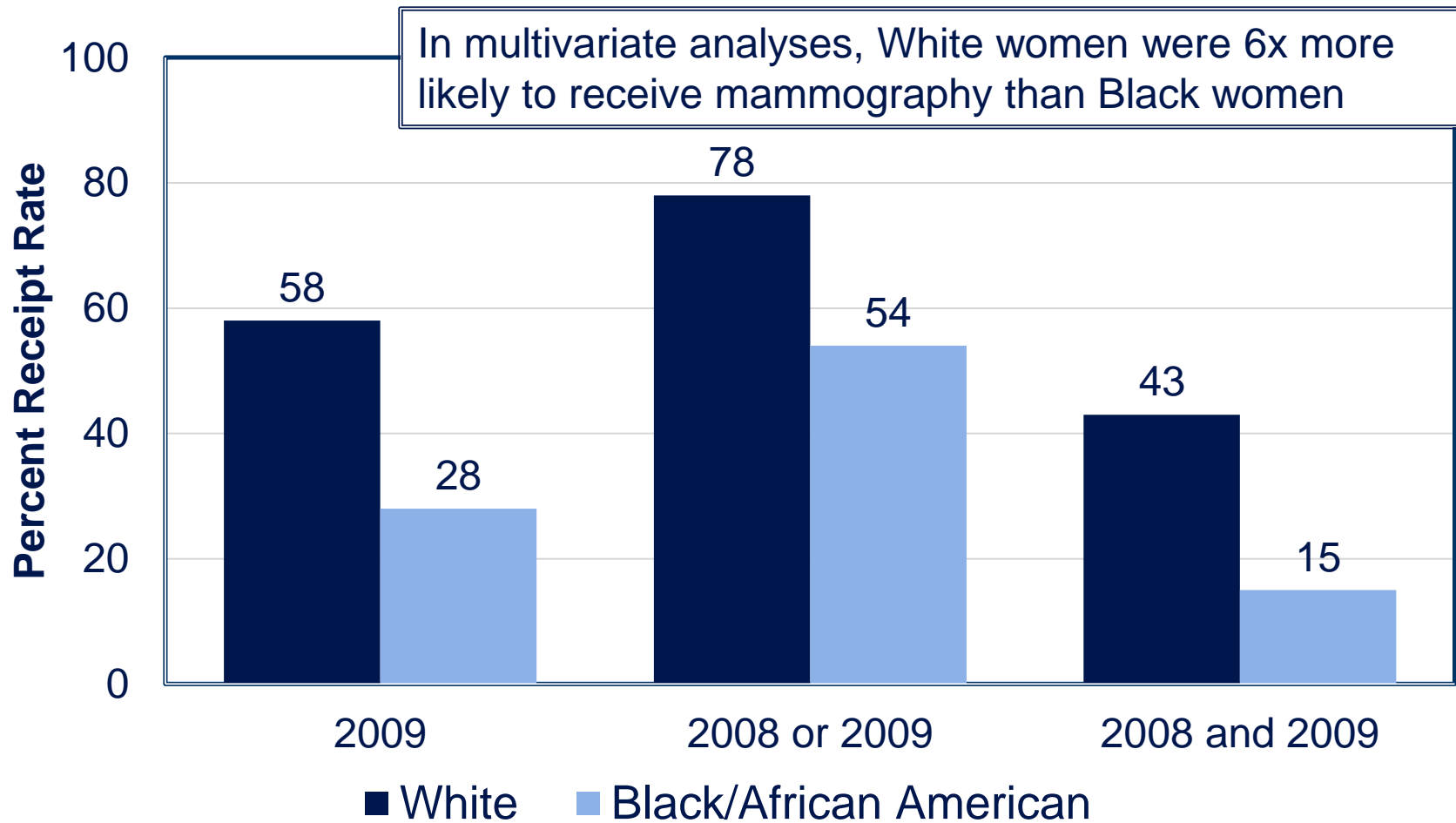
Pap test receipt among NC women ≥ 18 in 2008, 2009, or 2010



* North Carolina data from 2010 BRFSS

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Unadjusted mammography rates for Black & White women ages ≥ 40



Testing *Women Be Healthy*

- Randomized control trial with wait-list controls
- 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)
- Post-test interviews mean of 13 days after intervention

Indicators of Knowledge

- Definition of cancer
- Definition of mammogram
- Frequency of mammogram
- Whose job is it to do the breast exam
- What do you do when you find a lump?
- Definition of Pap test
- Frequency of Pap test
- Pap test instrument identification
- Identify ways to decrease anxiety for exams

- 9-item composite

Knowledge at baseline and post-test (% correct)

Indicator	Control		Experimental		Odds Ratio
	Baseline	Post-test	Baseline	Post-test	
Define cancer	39	42	32	39	NS
Define mammogram	45	48	41	55	2.33**
Mammogram frequency	22	21	15	29	3.09**
Who should do breast exam	90	89	90	91	NS
What should you do if find lump	71	81	70	72	NS
Define Pap test	38	52	40	51	NS
Frequency of Pap test	19	29	18	37	NS
Pap instrument identification	59	70	59	70	NS
Ways to reduce anxiety	41	48	43	58	NS
9-item composite (mean)	4.3	4.8	4.1	5.0	.38**

No statistically significant group differences at baseline; Odds Ratio represents significant regressions, controlling baseline knowledge; referent group is control group; red indicates significant knowledge gains within group



RCT Conclusions?

- *Women Be Healthy* was modestly effective in increasing women's knowledge about breast cancer screening
 - Ineffective in increasing women's cervical cancer knowledge
- Focus groups with women & instructor interviews
 - Women were uncomfortable with material related to cervical cancer
 - Inadequate instructional time spent on cervical cancer information
- Knowledge gains in the control group were interesting
 - Anecdotally, we heard from many women in the control group that they wanted to participate, diffusion of knowledge from the experimental group is possible; it is also possible that the interviews were a form of intervention

Some Noteworthy Anecdotes

- Women with developmental 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*)

Identification of Barriers to Screening

- Previous research: women with developmental disabilities are exceptionally fearful of these screening procedures (reported by women themselves and health care providers)
- Previous research: lowest screening rates for women who live at home with family caregivers
- In our sample, women who lived at home with family caregivers had the most limited knowledge about screenings

Sample of Family Caregivers

- In-depth qualitative interviews conducted with family caregivers of women in our sample (n=32)
- Race of participants: 45% Black; 3% Latina; 52% White
- Participants' relationship to women in our sample: mothers (78%), grandmothers, sisters & aunt
- Half of caregivers had household income < \$25,000/year
- 1/3 of family caregivers had disabilities

Family Caregivers' Reported Barriers & Facilitators to Screening

- *BARRIERS* to receipt of screening
 - Caregivers believe procedures are unnecessary for women with DD
 - Women with DD are uncomfortable with procedures
 - Women with DD are not sexually active
 - Women with DD are not prepared for exams
 - Medicaid coverage issues
 - Women with DD are shy, fearful
- *FACILITATORS* to receipt of screening
 - Caregiver explains procedure
 - Caregiver stays in exam room
 - Insurance
 - Anti-anxiety medications

Family Caregivers' Knowledge

- 64% of family caregivers correctly identified the screening guidelines for Pap tests
- 55% of family caregivers correctly identified the screening guidelines for mammography
- On balance, findings related to barriers, facilitators and caregivers' knowledge suggest targeted interventions for family caregivers are urgently needed
- Interventions for paid caregivers are probably imperative as well

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



Next Steps

- Field testing *Women Be Healthy 2* in seven sites with ~40 women with developmental disabilities
 - Preliminary evidence: women and instructors like the new content and it is feasible in this format
 - Developing an intervention targeted for caregivers is critically important
 - Family caregivers play major role in women's access to care
 - Multi-modal approach will be necessary
 - Workshops, health fairs, smart phone apps, website content, mailings, DVDs
- Test of the effectiveness of *Women Be Healthy 2* in increasing women's receipt of cervical & breast cancer
- Expand knowledge translation activities

Thank you!

- Participants, Advisory Board, community partner sites, instructors
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- Research team: Karen Luken, Jamie Swaine, Pam Dickens, Grace Wright, Glenna Williams, Esther Son, Sarah Dababnah, Rod Rose, Michelle Techler, Allison Ivie

For more info:

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