

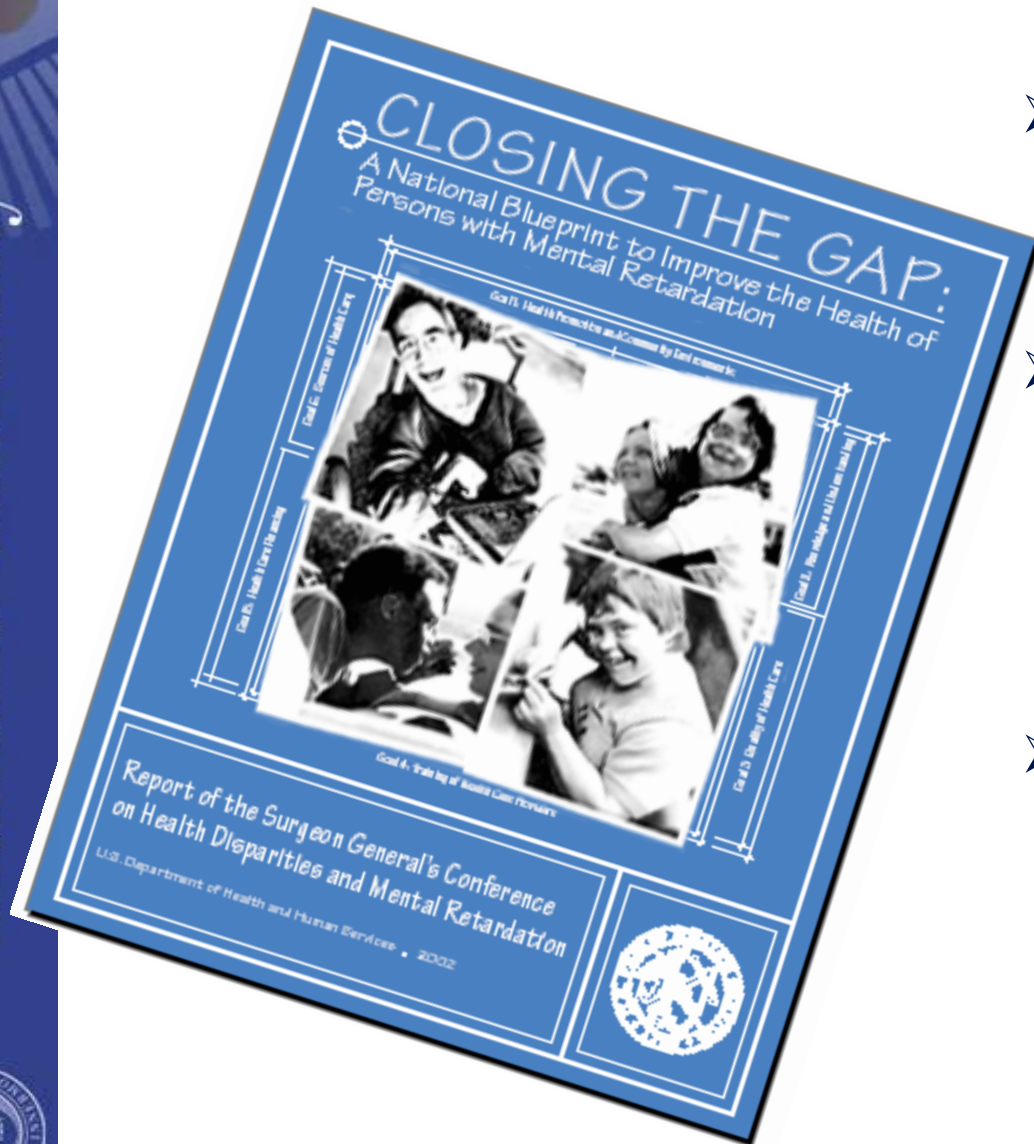
***Rigorous and Inclusive Health
Promotion Research with Women
with Disabilities: New Evidence
from the Field***

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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

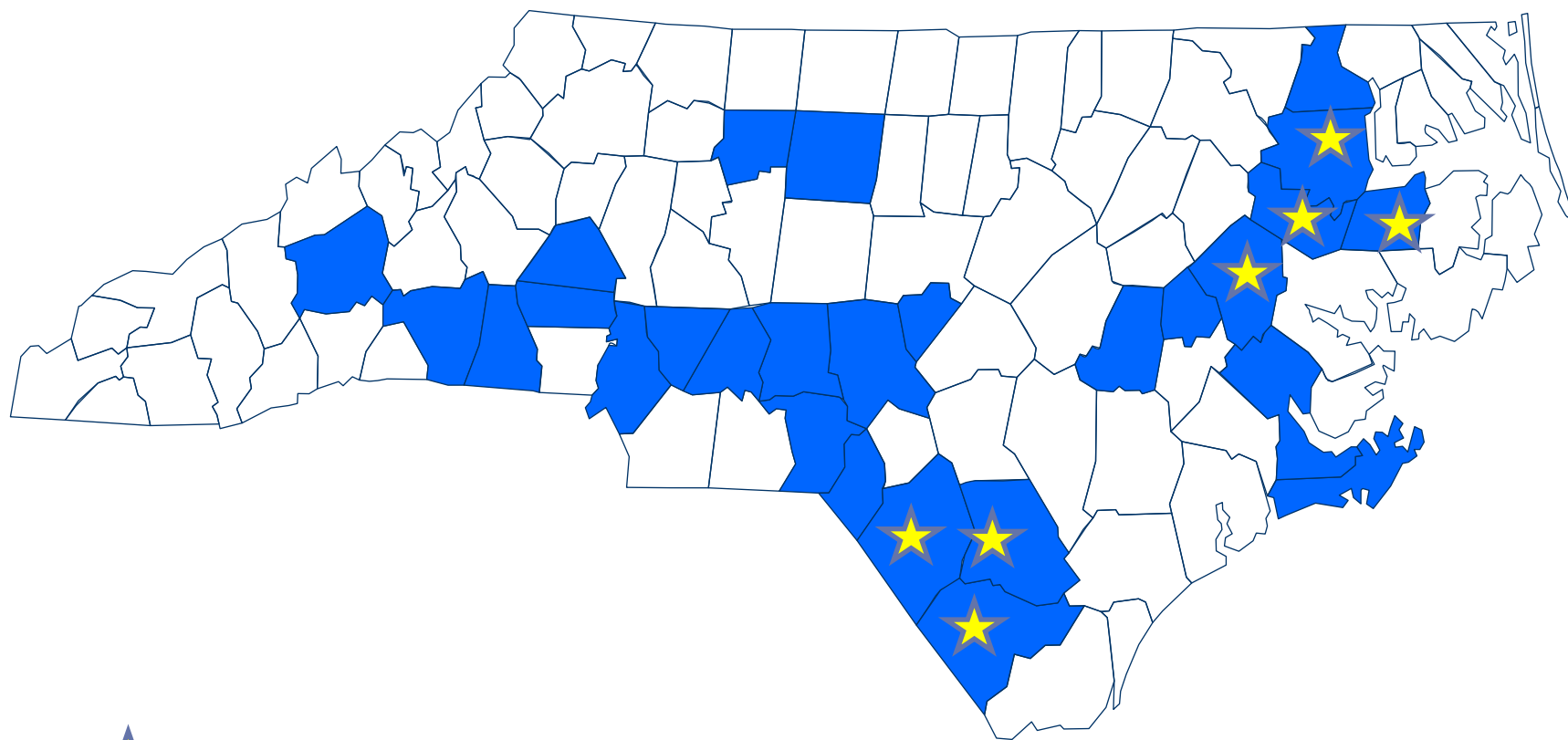
- Information sessions held at partner sites
- Sought assent *first* from women, then sought consent from guardians (if necessary)
- Research team explained WBH and the study
 - Multiple methods: video, written material, pictures, discussion, question & answer sessions, individual talks with women who 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

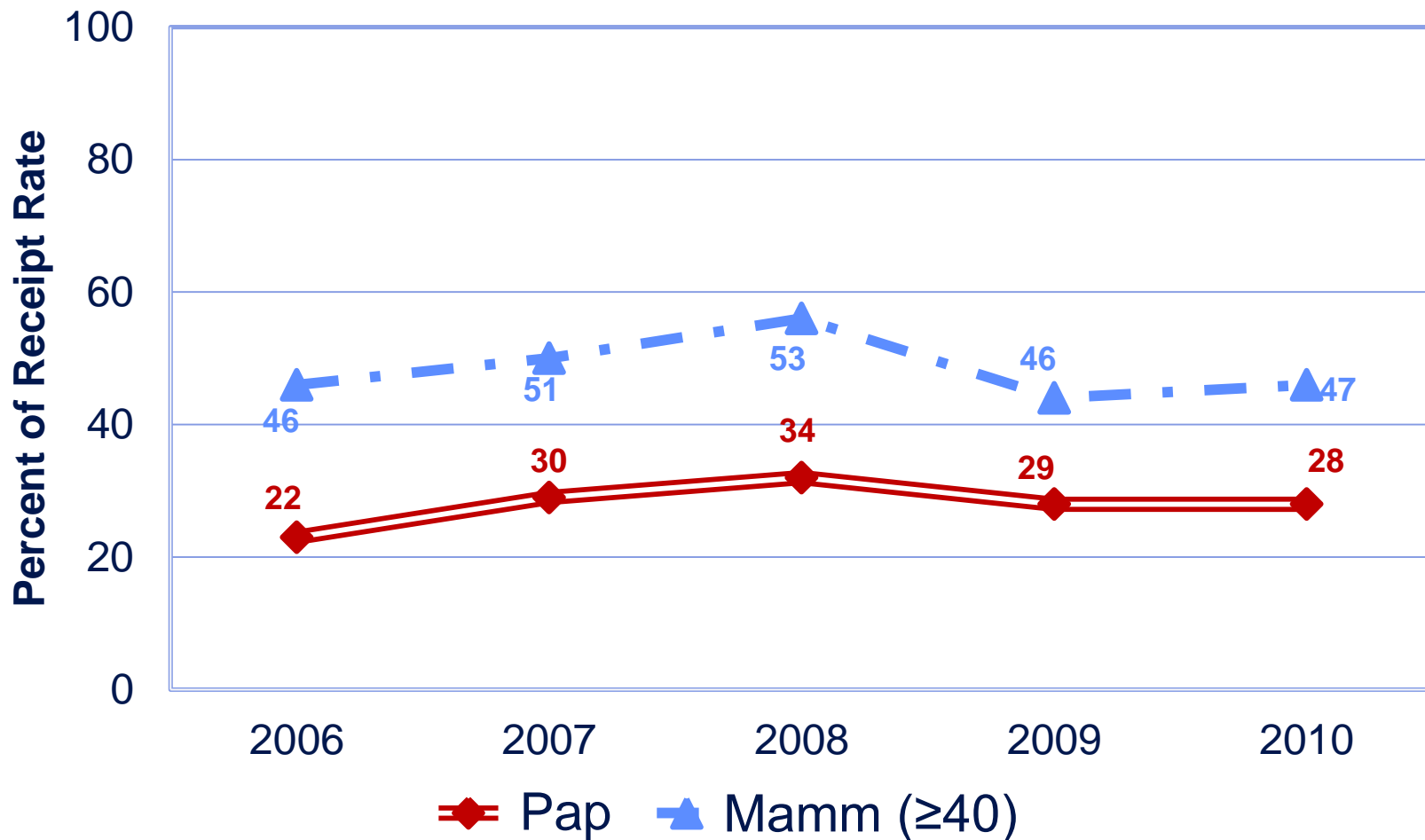


★ = Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor

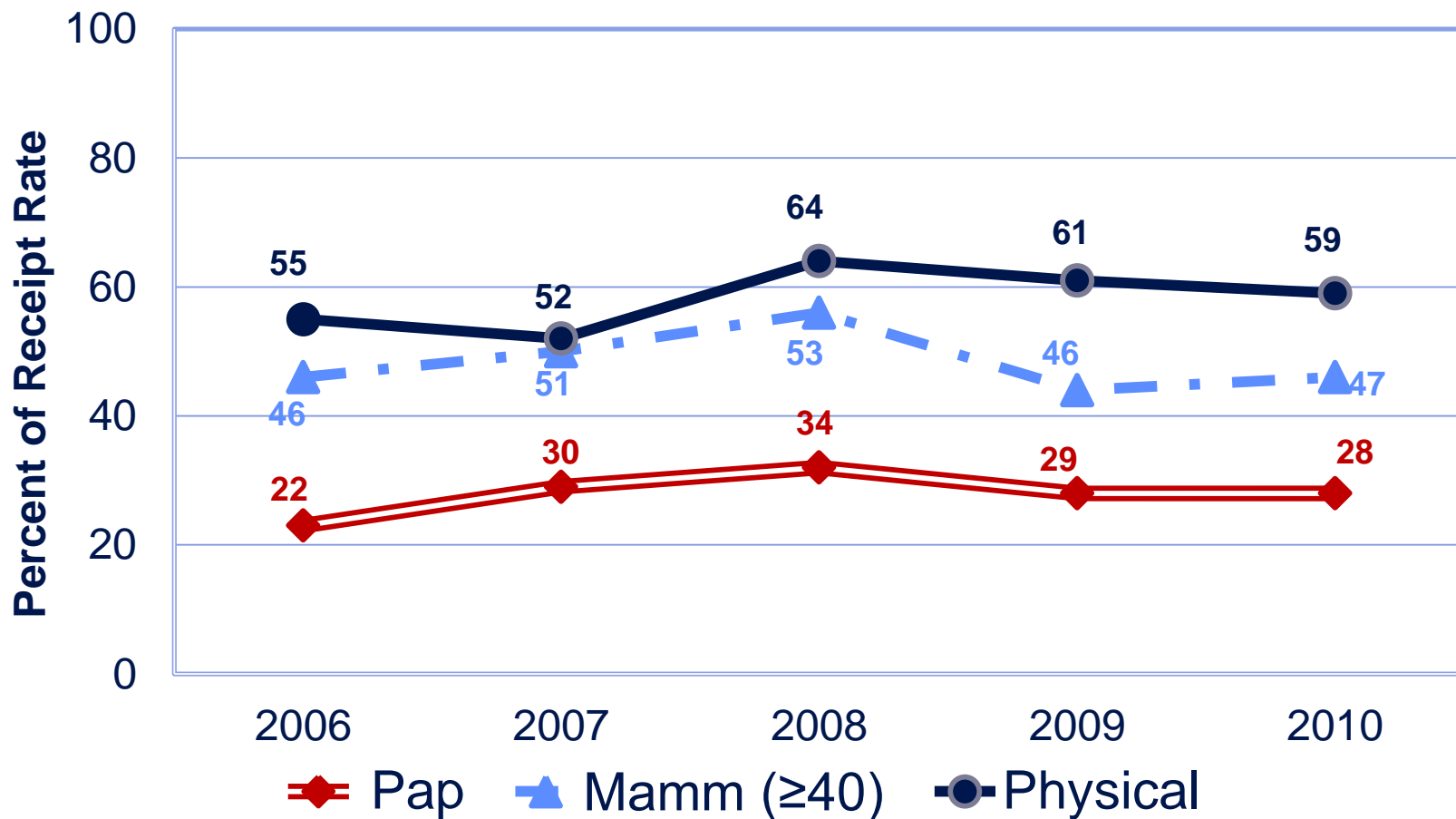
Goal: Determine Cervical & Breast Cancer Screening Rates

- 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

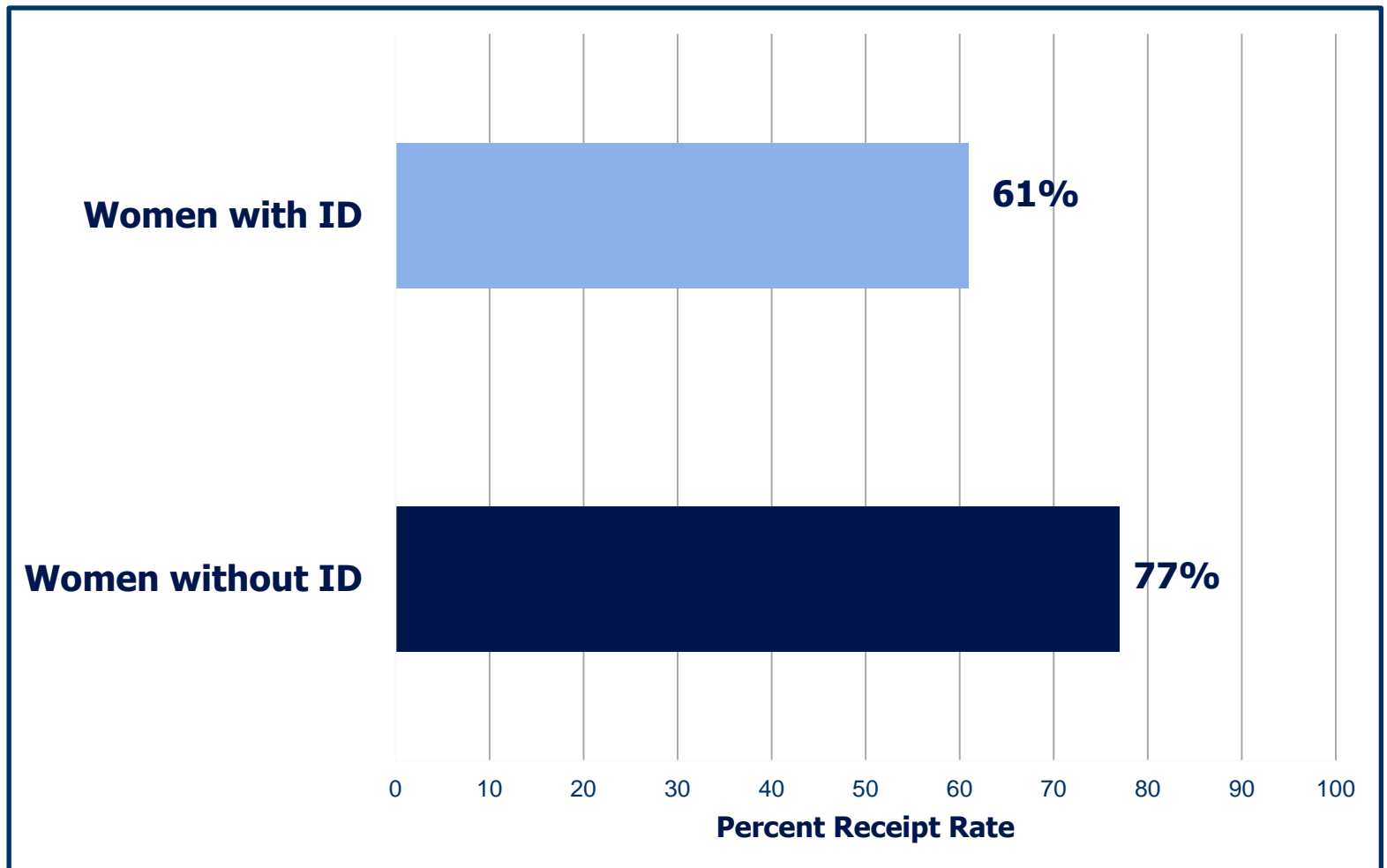
Percent of women receiving screening procedures, 2006-10



Percent of women receiving screening procedures, 2006-10



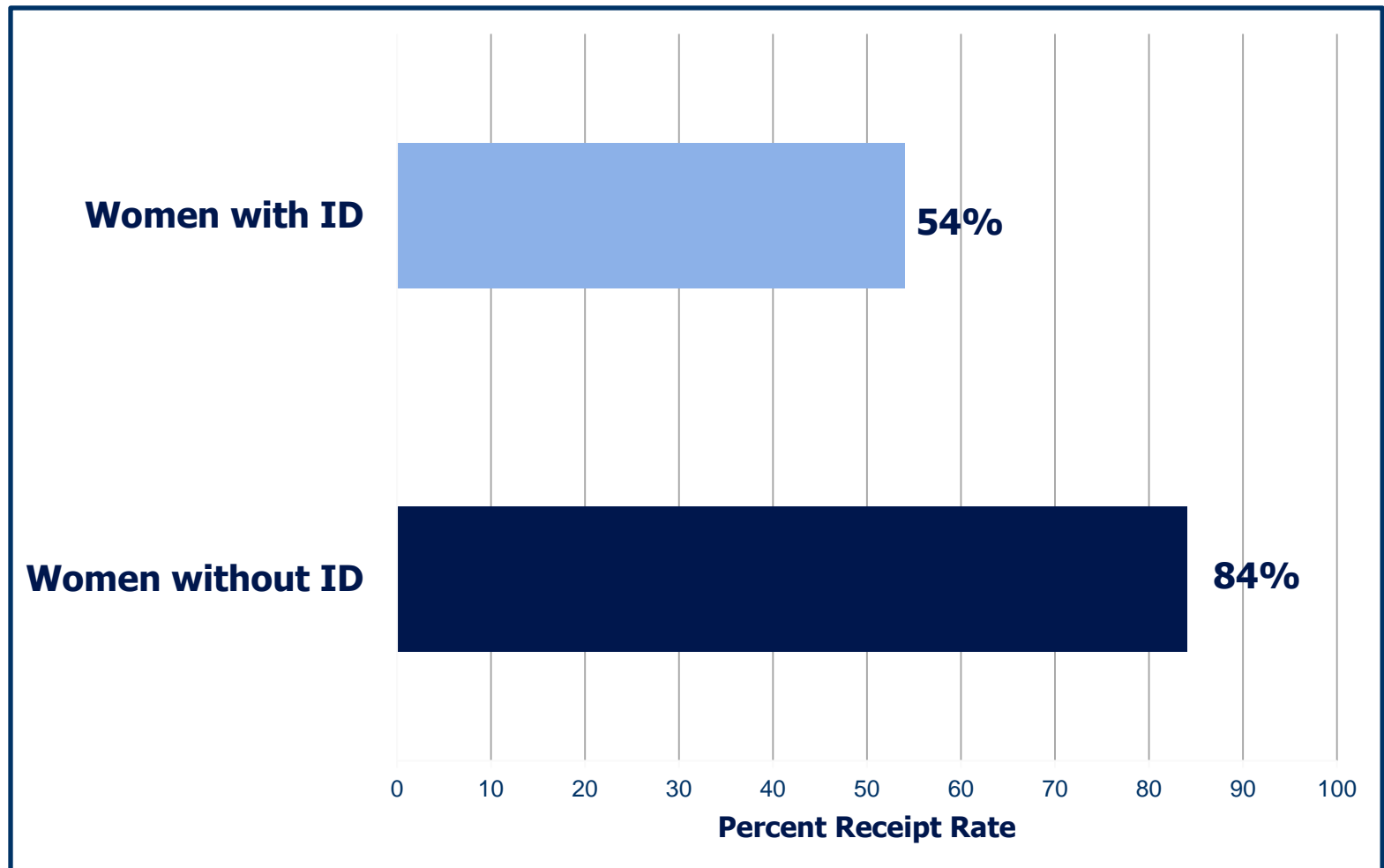
Mammography receipt among NC women ≥ 40 in 2009 or 2010



* North Carolina data from 2010 BRFSS

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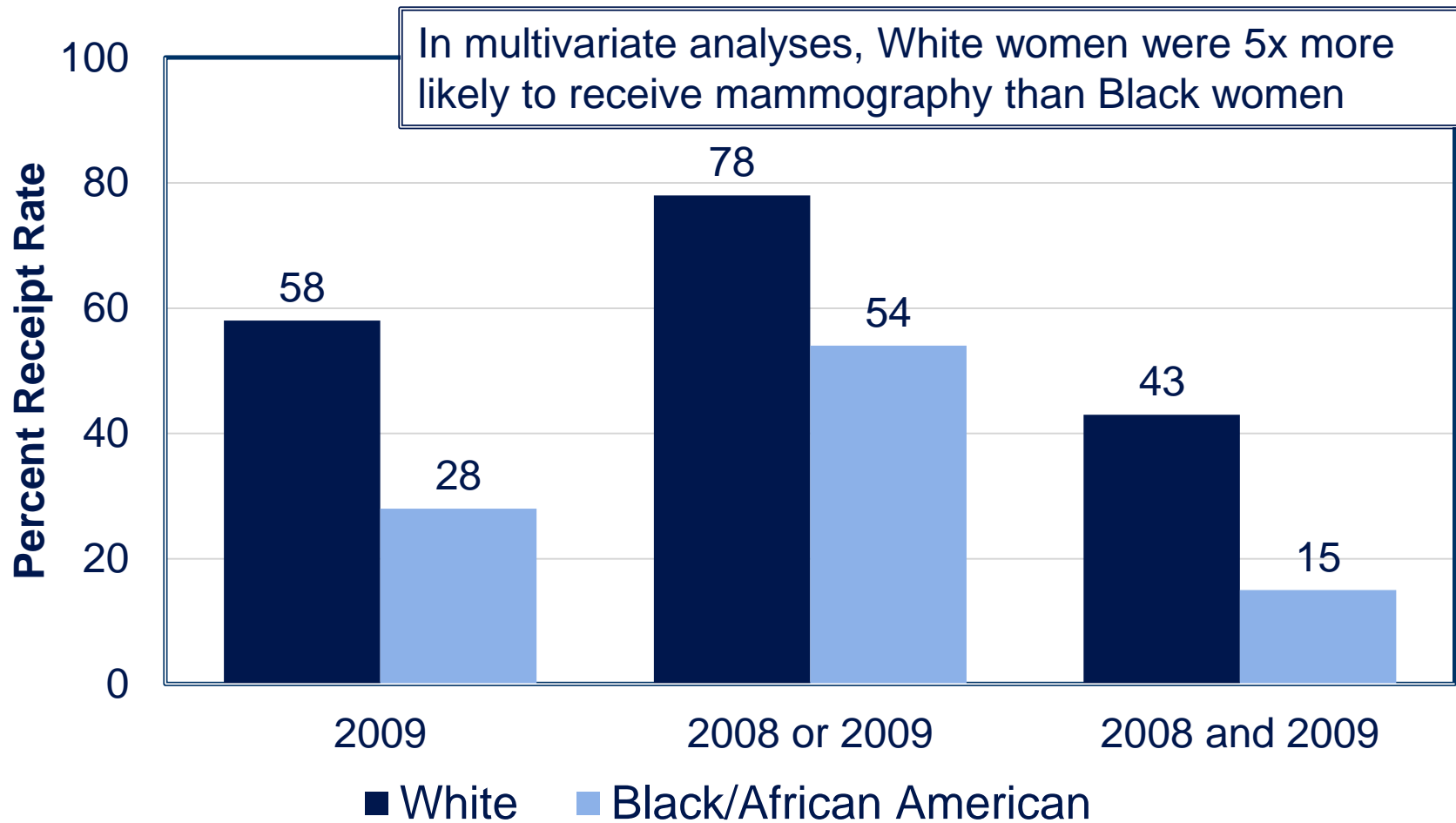
Pap test receipt among NC women ≥ 18 in 2008, 2009, or 2010



* 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

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; reference 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*)

Women Be Healthy 2

- Following the RCT, we revised the curriculum based off study findings, literature review, current screening guidelines, and interviews with instructors and participants.
- Class time increased to 22 hours
- Class information related to cervical health was increased to be comparable to breast health
- New activities and models were added
- The revised curriculum was pilot-tested with 35 women
- Women showed modest gains in knowledge with significant gains in overall knowledge scores



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

Knowledge Translation Process

- Trained Advisory Board on development of knowledge translation plan
 - Framework: Barwick & Lockett (2010) & Core Group's *Designing for Behavioral Change*
- Advisory Board prioritized audiences and mechanisms
 - For women with disabilities & family caregivers
 - Website
 - YouTube, Facebook
 - Checklists for health care visits
 - For advocates: research briefs
 - For researchers
 - Peer-reviewed journal articles, research briefs

Website

The website includes separate sections for:

- Women with Disabilities
 - Doctor visit worksheet, health screenings guidelines, fact sheets, research guide for self-advocates, health checklists
- Caregivers
 - Communication tips, notes for social workers and case managers, health checklists
- Health care professionals
 - Accommodating patients with disabilities
- Researchers
 - Links to peer-reviewed journal articles, research briefs
 - Revised curriculum

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



Facebook

- Launched *Women Be Healthy* Facebook site early March

<http://www.facebook.com/womenbehealthy>

122 people like us!!!

Facebook

The screenshot shows a Firefox browser window displaying the Facebook page for 'Women Be Healthy'. The browser's address bar shows 'www.facebook.com/womenbehealthy'. The Facebook interface includes a search bar, a navigation menu with 'Home', 'Find Friends', and 'Susan Parish', and a list of friends on the right. The main content area features a large group photo of ten women, a green female symbol icon, and the text 'Women Be Healthy' with '65 likes · 20 talking about this'. Below the photo is a description: 'Community Women Be Healthy is a curriculum designed to teach women with intellectual and developmental disabilities about cervical and breast cancer screenings.' The bottom of the page shows a navigation bar with 'Status', 'Photo', 'Ask Question', and 'Milestone' options, and a '7 Friends' section. The Windows taskbar at the bottom displays various application icons and the system clock showing '10:40 PM 4/1/2012'.

Brandeis University

YouTube

- Advisory Board prioritized this as an important way to reach women with disabilities
- Problem: Advisory Board more tech savvy than research team
 - The good news: they're trying to bring us along
- Two YouTube videos have been developed

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

Thank you!

- Participants, Advisory Board, community partner sites, instructors
- Funders: US Department of Education, NIDRR, Grant # H133G090124; NC Division of MH/DD/SAS, NC Office on Disability & Health; Lurie Institute for Disability Policy at Brandeis University
- 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>