

Cervical and Breast Cancer Screening of Women with Developmental Disabilities

Susan L. Parish, PhD, MSW
Nancy Lurie Marks Professor of Disability Policy
Director, Lurie Institute for Disability Policy

January 2012



Background

- Women with developmental disabilities have among the worst rates of cervical and breast cancer screening in the United States
 - Self-reported or proxy-reported data
- Barriers to care
 - Women's limited knowledge
 - Fear surrounding procedures
 - Physician's pejorative attitudes
- Our focus: Empowering women to be informed, assertive patients



Women Be Healthy intervention

- Intervention designed to improve women's knowledge and empowerment related to cervical and breast cancer screening
- Eight classes include hands-on experiential learning, field trip to GYN office, focus on empowerment AND knowledge
 - How to assert needs and ask questions with health care provider
 - How to describe symptoms
 - How to relax for stressful procedures (particularly pelvic exam)
 - Schedule of recommended procedures



Women Be Healthy used with ~500 women with intellectual disabilities

Satisfaction reported in initial pilot testing

Study Design

- Randomized control trial (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 interviews
- Randomized sample at each site
- Curriculum taught by on-site instructors who were not members of the research team
- Interviewers did not know the status of the participants
- Post-test interviews mean of 13 days after intervention
- Medical record data for receipt of screening

Sample

Characteristic	Control (n=84)	Experimental (n=91)
Race is Black	45%	45%
Has a child	15%	13%
Lives alone or with partner	8%	8%
Lives in formal residential setting	49%	42%
Lives with family caregiver	43%	50%
Age (mean)	41 years	40 years

No statistically significant differences between the groups on any measure

Indicators of Knowledge

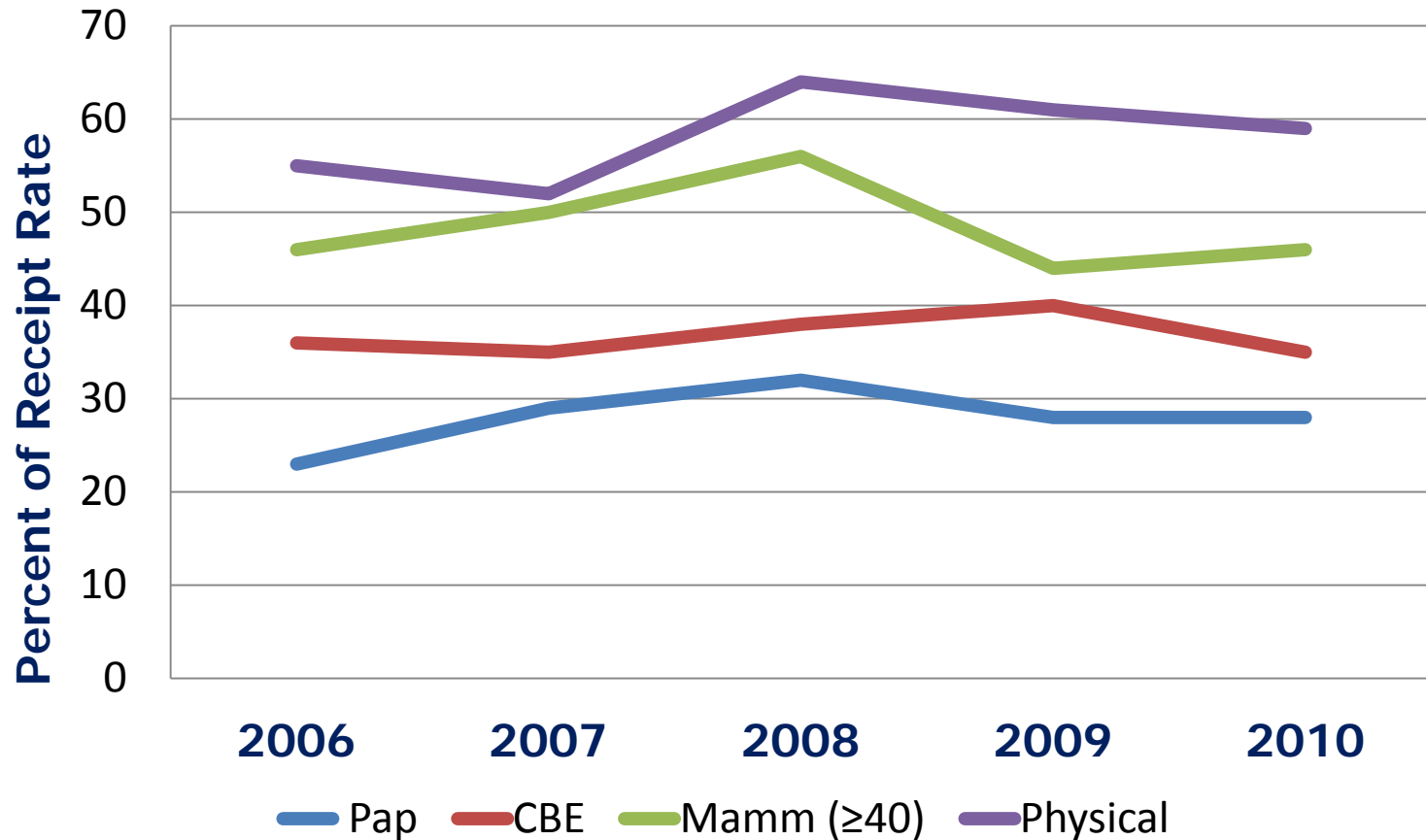
- Definition of cancer
- Definition of mammogram
- Frequency of mammogram
- Whose job is it to do the breast exam
- What do you do when you find a lump?
- Definition of Pap test
- Frequency of Pap test
- Pap test instrument identification
- Identify ways to decrease anxiety for exams

- 9-item composite

Analysis

- Regression models
- Covariate: baseline knowledge
- Insufficient variance for controls of living arrangement, whether woman had child, marital status

Rates of Receipt of Screening



CBE = Clinical breast exam



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

Anecdotal Evidence

- 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 they were “mentally retarded” (*sic*)
- 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 to the controls is possible; it is also possible that the interviews were a form of intervention

Implications

- Women with developmental disabilities have exceptionally 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



Thank you!

Co-authors: Karen Luken, Jamie Swaine, Rod Rose, at UNC-Chapel Hill; Esther Son at Brandeis

Funders: US Department of Education, NIDRR, Grant # H133G090124; North Carolina Office on Disability & Health; Lurie Institute for Disability Policy at Brandeis University

