Access to Cervical and Breast Cancer Screening for 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 late 2009 (controversial)
- Pap test guidelines changed in spring 2013
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.
Goal 1: Identify cervical & breast cancer screening determinants & 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 if they received screening versus 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
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
# Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 203 women</th>
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<tbody>
<tr>
<td>Race is Black</td>
<td>47%</td>
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<tr>
<td>Race is Asian, Native or Latina</td>
<td>3%</td>
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<tr>
<td>Has a child</td>
<td>13%</td>
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<tr>
<td>Lives alone or with partner</td>
<td>8%</td>
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<td>Lives in formal residential setting</td>
<td>40%</td>
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<tr>
<td>Lives with family caregiver</td>
<td>45%</td>
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<tr>
<td>Age (mean)</td>
<td>40 years (19 - 71 years range)</td>
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<tr>
<td>Impairment is mild or moderate</td>
<td>91%</td>
</tr>
<tr>
<td>Lives in rural area</td>
<td>75%</td>
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<tr>
<td>Insured</td>
<td>&gt;99%</td>
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Percent of women receiving screening procedures, 2006-10

Percent of Receipt Rate

Pap  Mamm (≥40)  Physical

2006  22  46  55
2007  30  51  52
2008  34  53  64
2009  29  46  61
2010  28  47  59
Pap test receipt among NC women ≥ 18 in 2008, 2009, or 2010

* North Carolina data from 2010 BRFSS

Percent Receipt Rate

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<tr>
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<th>Women with ID</th>
<th>Women without ID</th>
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<tr>
<td>54%</td>
<td></td>
<td>84%</td>
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LURIE INSTITUTE FOR DISABILITY POLICY
Determinants of Cervical Cancer Screening

Women were more likely to receive cervical cancer screening if they:

- Lived in a residential facility (as opposed to at home with family caregiver)
- Lived in a rural area
- Received care from an OB/GYN

Parish et al (2013) *Public Health Reports*
Mammography receipt among NC women ≥ 40 in 2009 or 2010

* North Carolina data from 2010 BRFSS

% Receipt Rate

Women with ID: 61%

Women without ID: 77%

* Lurie Institute for Disability Policy
Unadjusted mammography rates for Black & White women ages ≥40

In multivariable analyses, White women were 5x more likely to receive mammography than Black women.
Goal 2: Develop and test revised intervention to promote cervical and breast cancer screening

- *Women Be Healthy 2*
- Expansion of *Women Be Healthy* developed by Lunsky, Straiko, Armstrong; (revised by Havercamp, Dickens)
- In randomized control trial, *Women Be Healthy 1 improved* breast cancer screening knowledge of women with intellectual disabilities but not cervical cancer screening knowledge
- 3 focus groups with women with ID and 15 instructor interviews
- Women particularly uncomfortable with content related to cervical cancer
Women Be Healthy 2

- WBH2 is 22-session (1 hour twice/weekly) psychoeducational program for women with intellectual and developmental disabilities
- Content: anatomy, cancer, importance of screenings, how to communicate with health care provider, relaxation, field trip to GYN office & mammography site, multimedia, hands-on activities
- All activities geared for learners without literacy
- Doubled content on pelvic exams, cervical cancer & screenings from 3 to 6 hours
- Expanded relaxation activities
- Curriculum is **FREE** and available on the Lurie Institute for Disability Policy website: [http://lurie.brandeis.edu/women/curriculum.html](http://lurie.brandeis.edu/women/curriculum.html)
Goal 3: Test *Women Be Healthy 2*

- Randomized control trial
- 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)
- Compared WBH1, WBH2 to women in the control group
- 9 indicators of knowledge plus composite
Post-test Knowledge of Women with I/DD

- Definition of cancer
  - Note: adjusted for baseline, living arrangement & site type

- 9 item composite

![Graph showing predicted probabilities of correct response and mean scores for different groups.](image)
Predicted Probabilities: Post-test Breast Cancer Knowledge

Breast cancer knowledge indicator

- What to do if you find a lump: Predicted probabilities of correct response for different groups.
- Definition of mammogram: Predicted probabilities of correct response for different groups.
- Frequency of mammogram: Predicted probabilities of correct response for different groups.
- Whose job is it to do the breast exam: Predicted probabilities of correct response for different groups.

Note: adjusted for baseline, living arrangement & site type
Post-test Cervical Cancer Knowledge of Women with I/DD

Cervical Cancer Knowledge Indicator

- Definition of Pap test
- Frequency of Pap test
- Pap test picture identification
- Identify ways to decrease anxiety for pelvic exam

Note: adjusted for baseline, living arrangement & site type
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.
Some Important Anecdotes

- Some women with ID 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 ID

- Two physicians wrote on medical record forms “not needed because mentally retarded” [sic]
Conclusions

- Women with intellectual and developmental disabilities do not receive cervical and breast cancer screening according to clinical guidelines.
- Assertive efforts are needed to ensure that Black women with intellectual and developmental disabilities receive mammography.
- Women with intellectual and developmental disabilities can benefit from a tailored intervention to improve their knowledge about these screenings.

- Women with ID who live in the community are at risk for developing HPV and cervical cancer and should receive Pap tests according to clinical guidelines.
Check us out on YouTube!

http://www.youtube.com/watch?v=jgTrbWUdclg
Thank you!

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- Research team: Karen Luken, Jamie Swaine, Pam Dickens, Grace Wright, Glenna Williams, Esther Son, Sarah Dababnah, Rod Rose, Michelle Techler

For more info: http://lurie.brandeis.edu/women/index.html