Women Be Healthy 2: A promising new community-based intervention

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for ONCODEFI
Background: Breast Cancer Screening for U.S. Women with DD

- Existing research suggests women with intellectual disabilities have among the worst rates of breast cancer screening in the United States

- 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
Aim 1: Identify breast cancer screening rates from objective data

- Existing screening estimates derived from self-reported or proxy-reported interview data
  - Biased reporting is highly likely by all women regardless of their disability status
- 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
### 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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<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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<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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</table>
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

- Mamm (≥40)
- Physical

Percent of Receipt Rate

- 2006: 46
- 2007: 51
- 2008: 53
- 2009: 46
- 2010: 47
Mammography receipt among NC women $\geq 40$ in 2009 or 2010

* North Carolina data from 2010 BRFSS
In multivariable analyses, White women were 5x more likely to receive mammography than Black women.
Aim 2: Develop & test revised intervention to promote cervical and breast cancer screening

- **Women Be Healthy 2**
- Expansion of **Women Be Healthy** (Lunsky, Straiko, Armstrong)
- In randomized control trial, **Women Be Healthy** improved breast cancer screening knowledge of women with intellectual disabilities but not cervical cancer screening knowledge
- Developed after focus groups and interviews with participants and lay health educators
- **Women Be Healthy 2** is 22-session (1 hour twice/weekly) psycho-educational program for women with intellectual disabilities
- Delivered by lay health educators following 5-hour training
- All activities geared for learners without literacy
- 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)
Women Be Healthy 2 content

- Anatomy using models and dolls
- Cancer & importance of cancer screenings
- Importance of healthy behaviors
- Communicate with health care provider
- Know what is normal for you
- Know when you need to visit the health care provider
- Relaxation exercises
- Field trips to GYN office & mammography site
- Multimedia, hands-on activities

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Test of *Women Be Healthy 2*

- Randomized control trial
- 21 disability service organization sites across North Carolina in the US
- 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)
- 4 indicators of breast cancer knowledge
Predicted Probabilities: Post-test Breast Cancer Knowledge

Breast cancer knowledge indicator

What to do if you find a lump
Definition of mammogram
Frequency of mammogram
Whose job is it to do the breast exam

Note: adjusted for baseline knowledge, living arrangement & site type
Conclusions

- Women with intellectual disabilities have low rates of breast cancer screening and rates are particularly poor for Black and African American women with intellectual disabilities.
- Women with intellectual disabilities can benefit from a targeted intervention geared to learners with low literacy.
- Modest knowledge gains in breast cancer indicate greater duration of content may be needed.
- Clear need for targeted intervention with women, caregivers, health care providers.
Thank you!

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

For more info: [http://lurie.brandeis.edu/women/index.html](http://lurie.brandeis.edu/women/index.html)