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)
Randomized Control Trial of Women Be Healthy

- Identification of screening barriers
  - Medical records
  - Family caregivers
- Evaluation of intervention implementation fidelity
- Determine screening rates from medical records
- Develop recruitment & consent protocol
- Develop WBH2
- Examine racial disparities in screening
- Feasibility & acceptability trial of WBH2
- Assessment of women's accuracy in reporting procedures
- Examine racial disparities in screening

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

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

Pap

Mamm (≥40)
Percent of women receiving screening procedures, 2006-10

Percent of Receipt Rate

Year: 2006 2007 2008 2009 2010

Pap: 22 30 34 29 28

Mamm (≥40): 46 51 53 46 47

Physical: 55 52 64 61 59

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Mammography receipt among NC women ≥ 40 in 2009 or 2010

* North Carolina data from 2010 BRFSS
Pap test receipt among NC women $\geq 18$ in 2008, 2009, or 2010

- **Women with ID**
  - 54%

- **Women without ID**
  - 84%

* North Carolina data from 2010 BRFSS

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Unadjusted mammography rates for Black & White women ages ≥40

In multivariate analyses, White women were 6x more likely to receive mammography than Black women.
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)

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

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

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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

65 people like us!!!
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
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
- 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](http://lurie.brandeis.edu/women/index.html)