Cervical and Breast Cancer Screening of Women with Intellectual Disabilities: Evidence of Inadequate Receipt

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

April 2012
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 ~1 month ago
Background: Cervical & Breast Cancer Screening for U.S. Women with ID

- Existing research suggests women with intellectual and 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
- Women with intellectual disabilities have both protective and risk factors for cervical and breast cancer
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 intellectual 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
## Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 202 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 paid/formal residential setting</td>
<td>46%</td>
</tr>
<tr>
<td>Lives with family caregiver</td>
<td>46%</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>41 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
Percent of women with ID receiving screening procedures, 2006-10

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

LURIE INSTITUTE FOR DISABILITY POLICY
Mammography receipt among NC women ≥ 40 in 2009 or 2010

Women with ID

Women without ID

Percent Receipt Rate

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

* North Carolina data from 2010 BRFSS
Some Noteworthy Anecdotes

- Women with intellectual 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” \((sic)\)
Conclusions

- Women with intellectual disabilities have exceptionally low rates of cervical and breast cancer screening

- Clear need for targeted intervention with women, caregivers, health care providers
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