Working with Stakeholders to Adapt a Cancer Screening Education Program for Native American Women with Intellectual Disabilities

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Research Objective: To identify facilitators and barriers related to cancer screening for Native American (NA) women with intellectual and/or developmental disabilities (IDD) in order to culturally adapt an existing breast and cervical cancer education program for AI women with IDD.

Aim 1: Build partnerships with NA groups and communities that express a need for cancer prevention for NA women experiencing IDD, in order to collaboratively adapt the Women Be Healthy 2 (WBH2) program.

Aim 2: Adapt WBH2 with input from NA women experiencing IDD (n=24), their caregivers (n=24), their health care providers (n=24), and Native community members (n=12).

What is an intellectual disability? Difficulty with intellectual functioning and in many everyday social and practical skills.

What is a developmental disability? A group of conditions due to an impairment in physical function, learning, language and/or behavior.

Both begin when a person is young, affect day-to-day functioning, and usually last throughout a person’s lifetime.

Methods: Community-Engaged Ecosocial Qualitative Approach

Making systems more accessible: improving the knowledge and awareness of health care providers

Creating linkages to facilitate screenings: NA women with IDD to programs; program-to-program

Improving cancer screening outcomes for NA women with IDD (e.g. # of screenings, increased knowledge)

Improving individual knowledge about screening for women with disabilities: NA Women with IDD and care providers

Essential Elements1 of the WBH2 Program

Advisory Board’s Initial WBH2 Adaptation Recommendations

<table>
<thead>
<tr>
<th>WHAT?</th>
<th>HOW?</th>
<th>WHO?</th>
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<tbody>
<tr>
<td>1. What messages will be communicated?</td>
<td>1. What are the recommended teaching methods?</td>
<td>1. What skills and experiences will help facilitators deliver essential content clearly?</td>
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<td>2. What knowledge will be increased?</td>
<td>2. How many sessions should be delivered, for how long, and over what period of time?</td>
<td>2. What other characteristics, like credibility with participants, values, and buy-in, will help a facilitator successfully deliver the approach?</td>
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<td>3. What skills will be developed?</td>
<td>3. What setting and environment will best support learning?</td>
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WHAT?
- Bridge curriculum concepts to cultural knowledge (e.g. beliefs about disability & the sacredness of the female body)
- Include holistic approaches (mind/body/spirit)
- Reduce the frequency and duration of the curriculum

Next steps: Complete qualitative data collection and adapt program

Qualitative data collection, two “communities” (one urban, one rural)
Assess WBH2’s “fit” based on outcomes from qualitative data analysis
Adapt to support delivery of the program’s “essential elements” (e.g. adapt to ensure relevance and program participation)

Advisory Board Engagement

- Project Advisory Board includes 6 individuals representing NA health, cancer programming, and disability resources in Arizona.
- WBH2 adaptation (Aim 2) guided by Advisory Board feedback via individual surveys and focus group.

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References Cited