Improving Shared Decision-Making about Cancer Screening Among American Indian Women Experiencing Intellectual and/or Developmental Disabilities (IDD)

NORTHERN ARIZONA UNIVERSITY

THE UNIVERSITY OF ARIZONA Cancer Center

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2017-2019

Overview

- Introductions & project support
- Cancer screening disparities and women with IDD
- Project activities
- Future goals
- Group discussion

Introductions and Project Support

About us

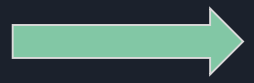
- Julie Armin, PhD
  - Co-Principal Investigator, University of Arizona, University of Arizona Cancer Center
  - Assistant Professor, Research, Department of Family & Community Medicine
- Heather Williamson, DrPH
  - Co-Principal Investigator, Northern Arizona University
  - Assistant Professor, Occupational Therapy, Center for Health Equity Research
- Julie Baldwin, PhD
  - Co-investigator, Northern Arizona University
  - Professor and Director, Center for Health Equity Research

Project funded as a *Planning Grant* from the Partnership for Native American Cancer Prevention

Cancer Screening Disparities and Women with IDD

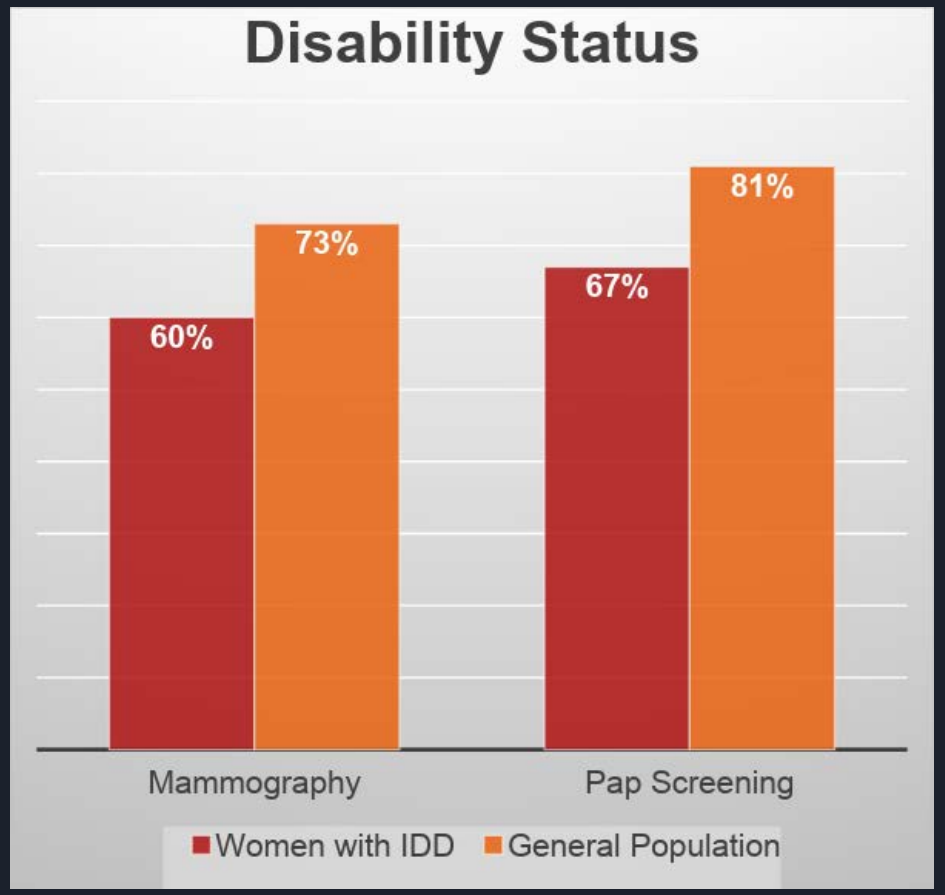
Cancer and Women with IDD

- Longer life expectancy
- Cancer incidence similar to general population
- Cancer second leading cause of death



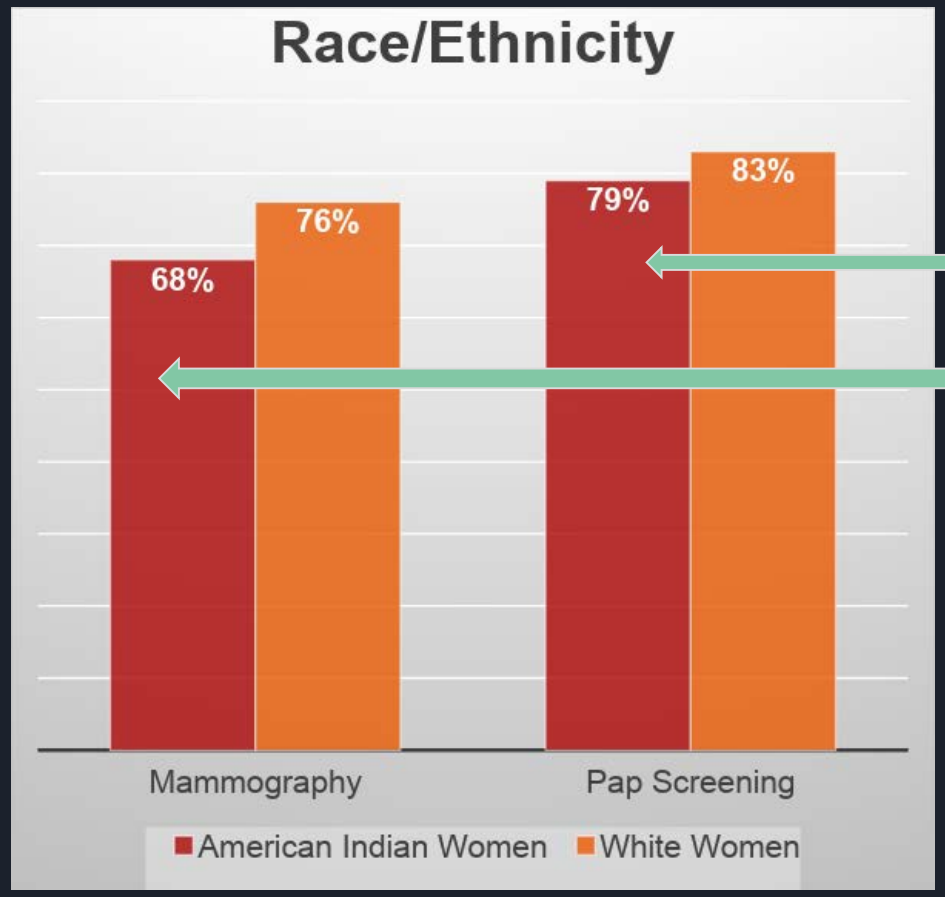
- Women with IDD: Rate of sexual assault is 12 times the rate of women without disabilities
- Women with IDD receive services when disease process is more advanced

Cancer Screening Disparities for Women with Intellectual and/or Developmental Disabilities (IDD)



Source(s): Parish & Saville, 2006; National Core Indicators, 2016; National Cancer Institute, 2015

Cancer Screening Disparities for American Indian Women



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American Indian women living in the Southwest US:

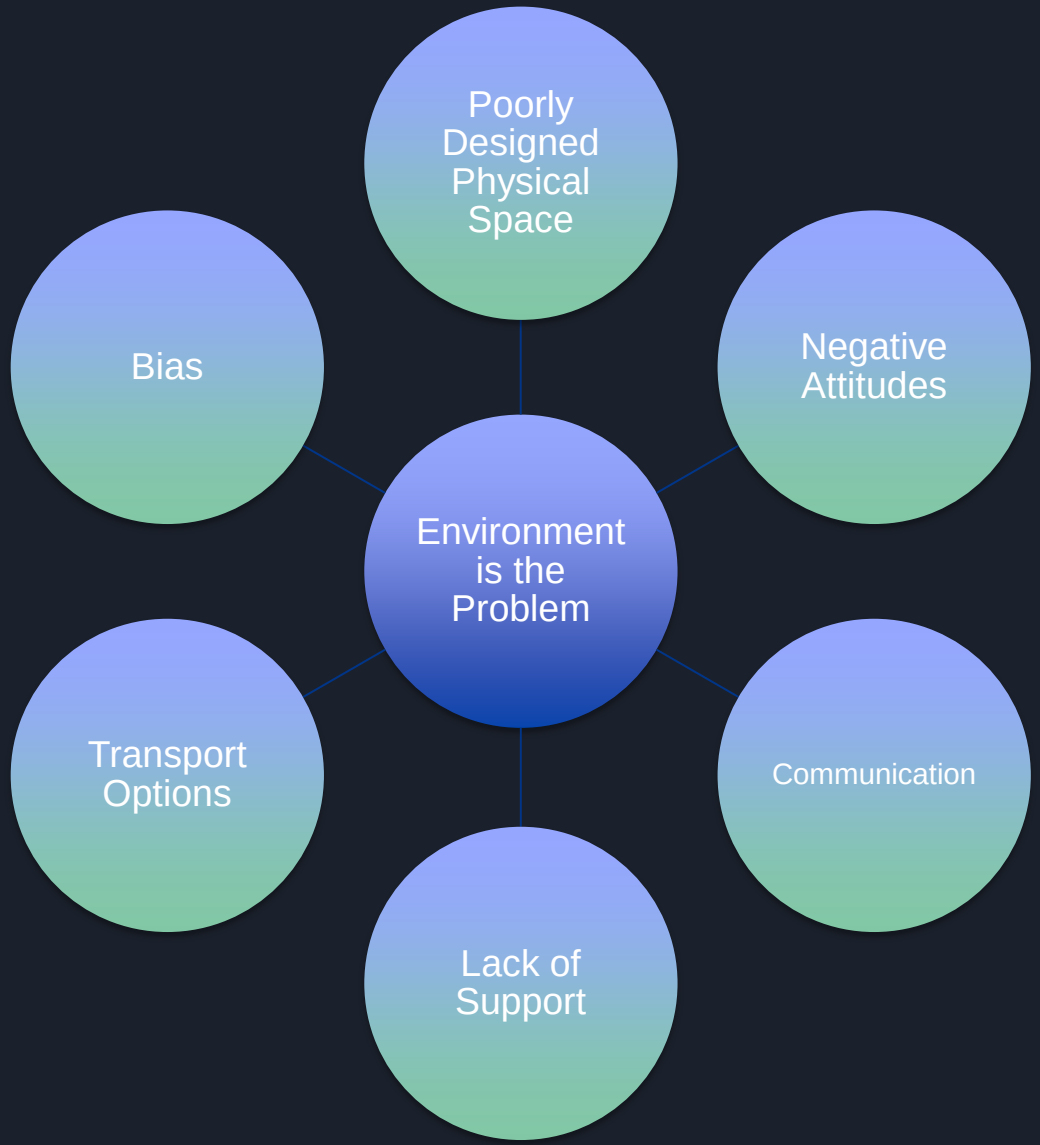
Cervical cancer screening 76%

Breast cancer screening: 61.5%

Source(s): Cobb, Epsey, & King, 2014

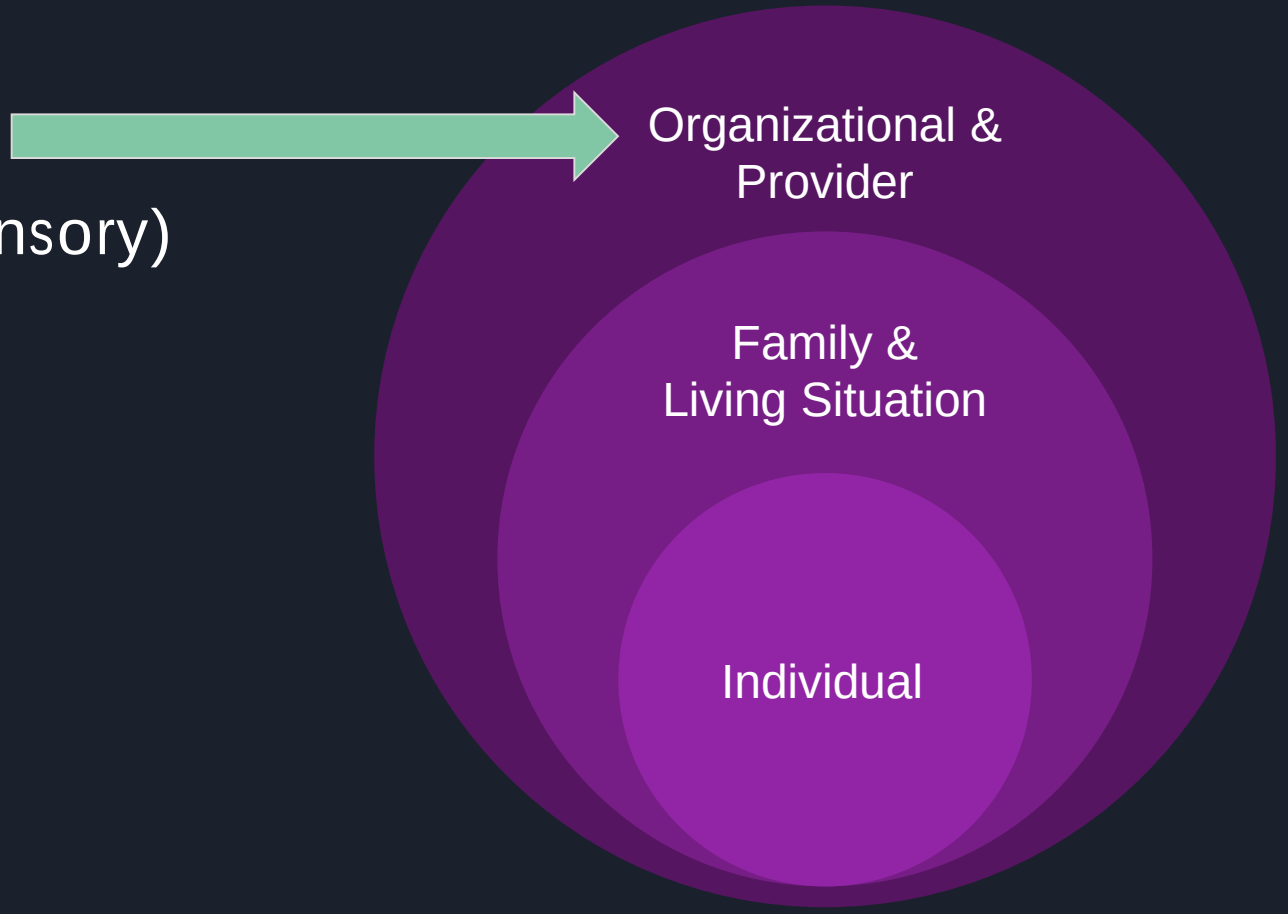
Social Model of Disability

- Disability experience defined by societal limitations



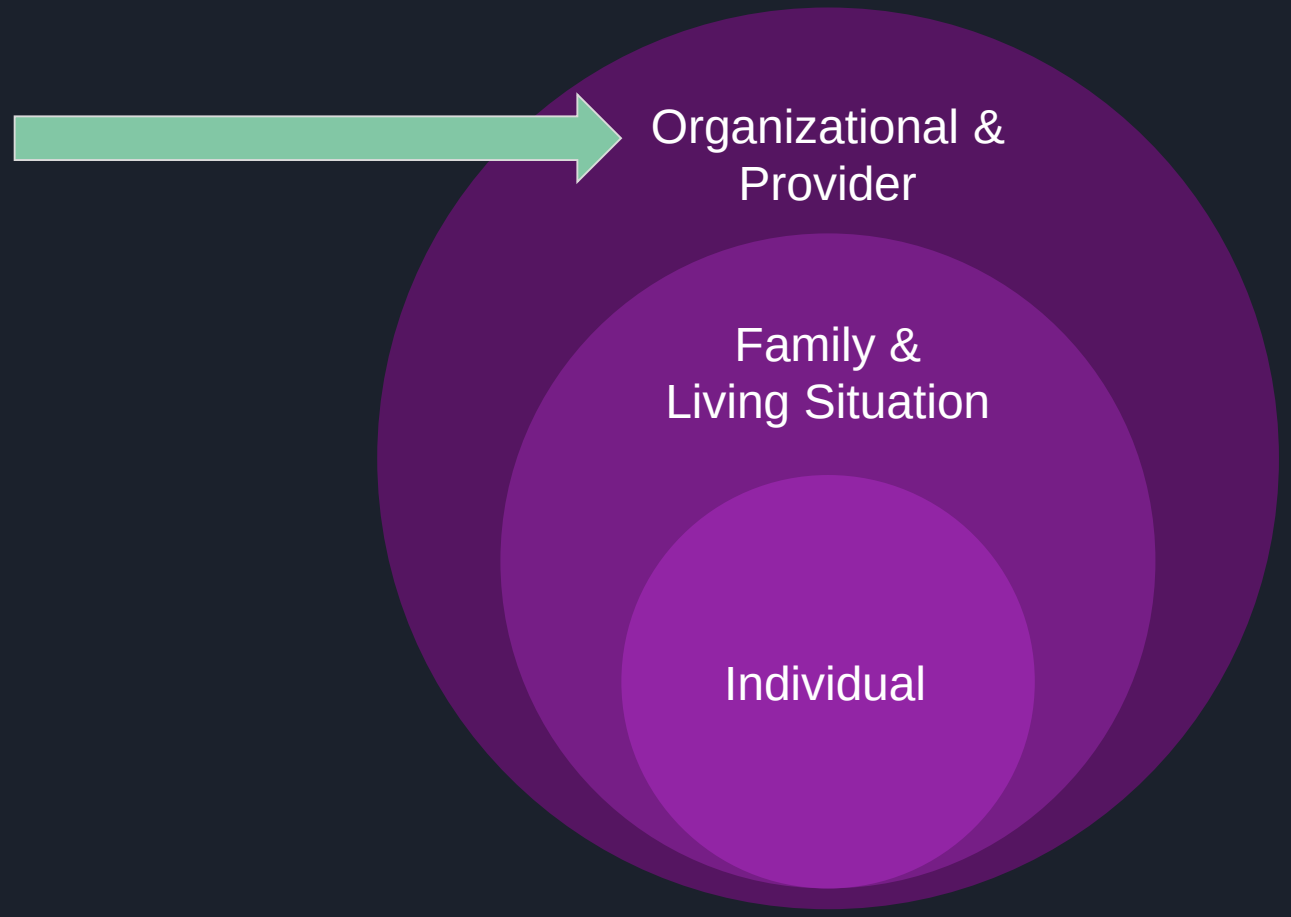
Why are women with IDD less likely to receive screenings?

- Organizational
  - Accessibility (physical, sensory)
  - Lack of coverage
  - Rural
  - Transportation



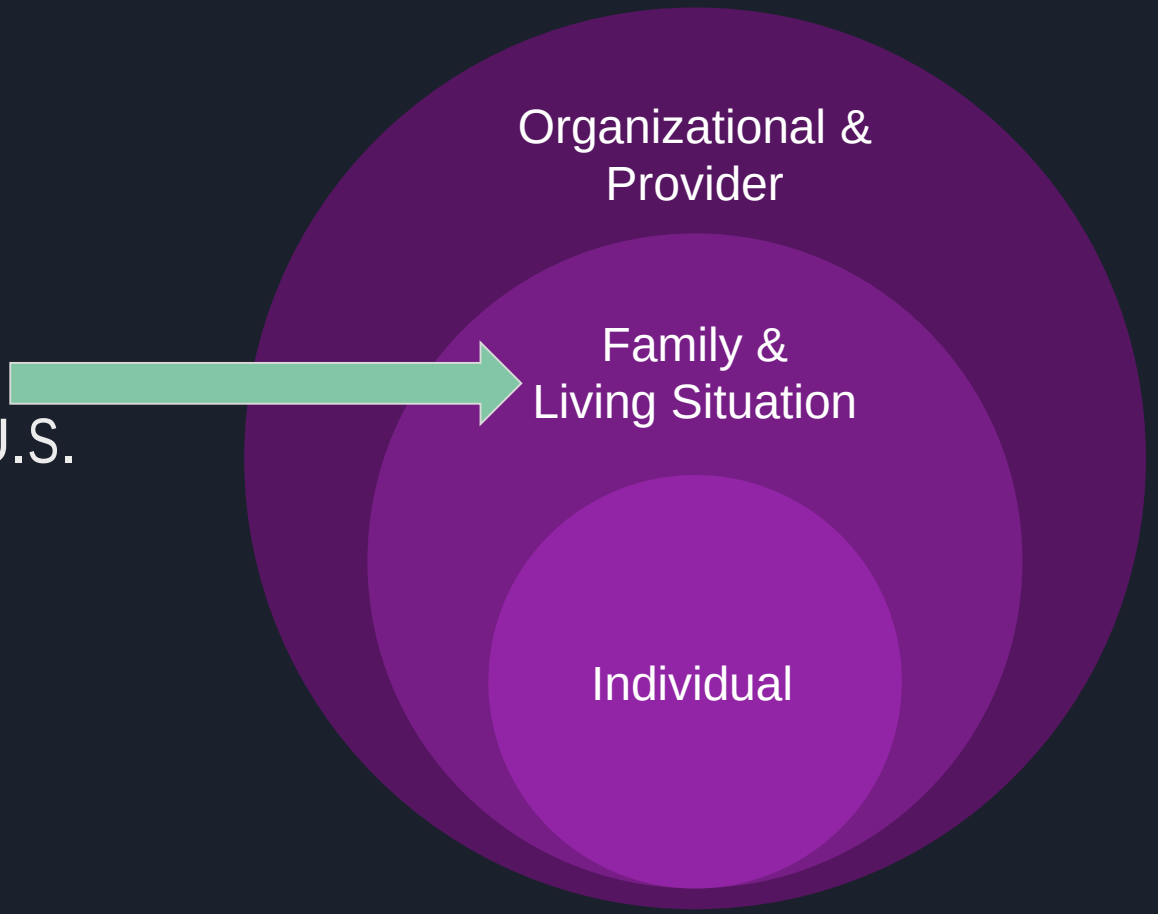
Why are women with IDD less likely to receive screenings?

- Provider
  - Provider misperceptions
  - Provider hesitancy
  - Provider communication
  - Provider knowledge



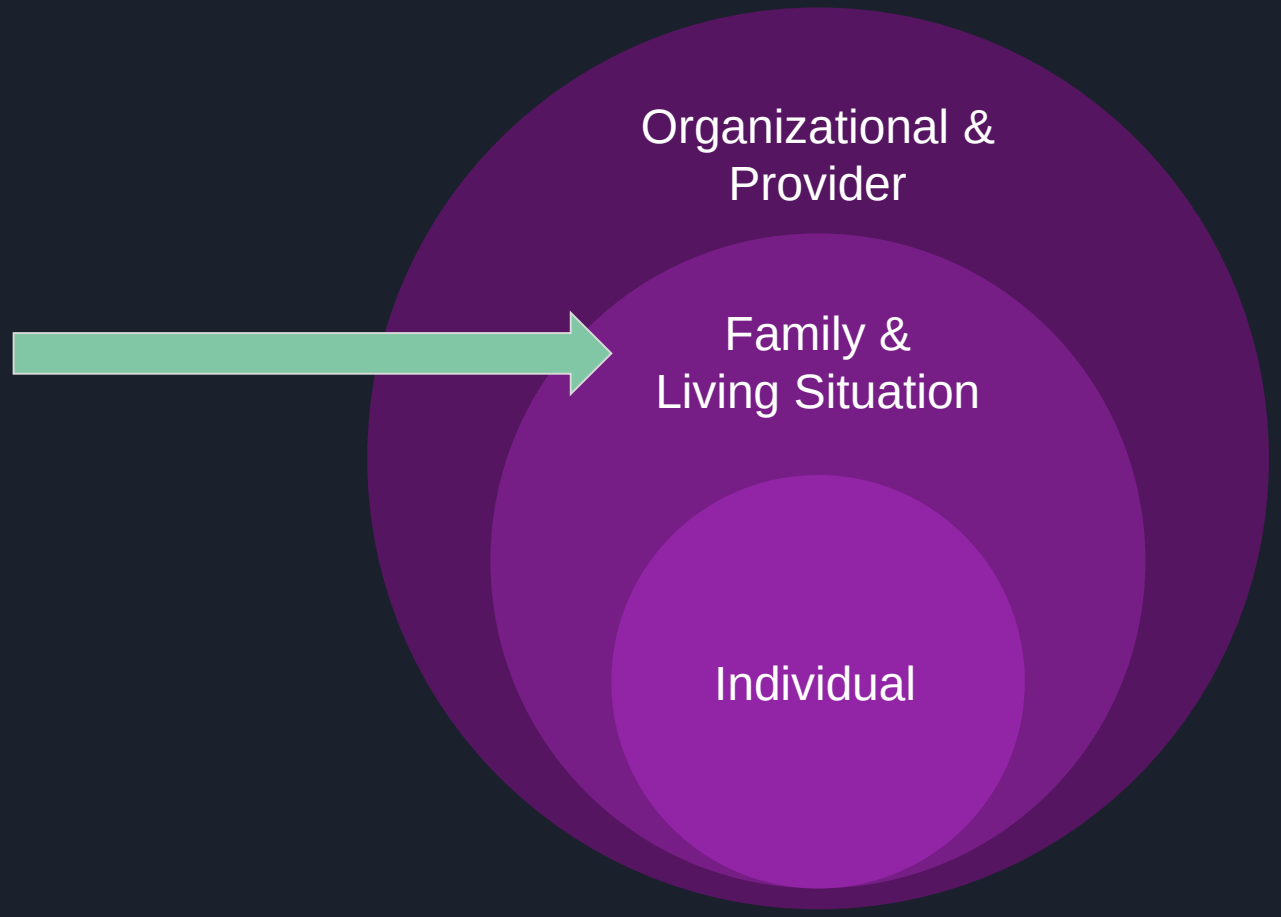
Why are women with IDD less likely to receive screenings?

- Living situation
  - With family: 78% AZ, 71% U.S.
  - Supervised setting: 5% AZ, 13% U.S.
  - Alone: 17% AZ, 16% U.S.
- Race/Ethnicity



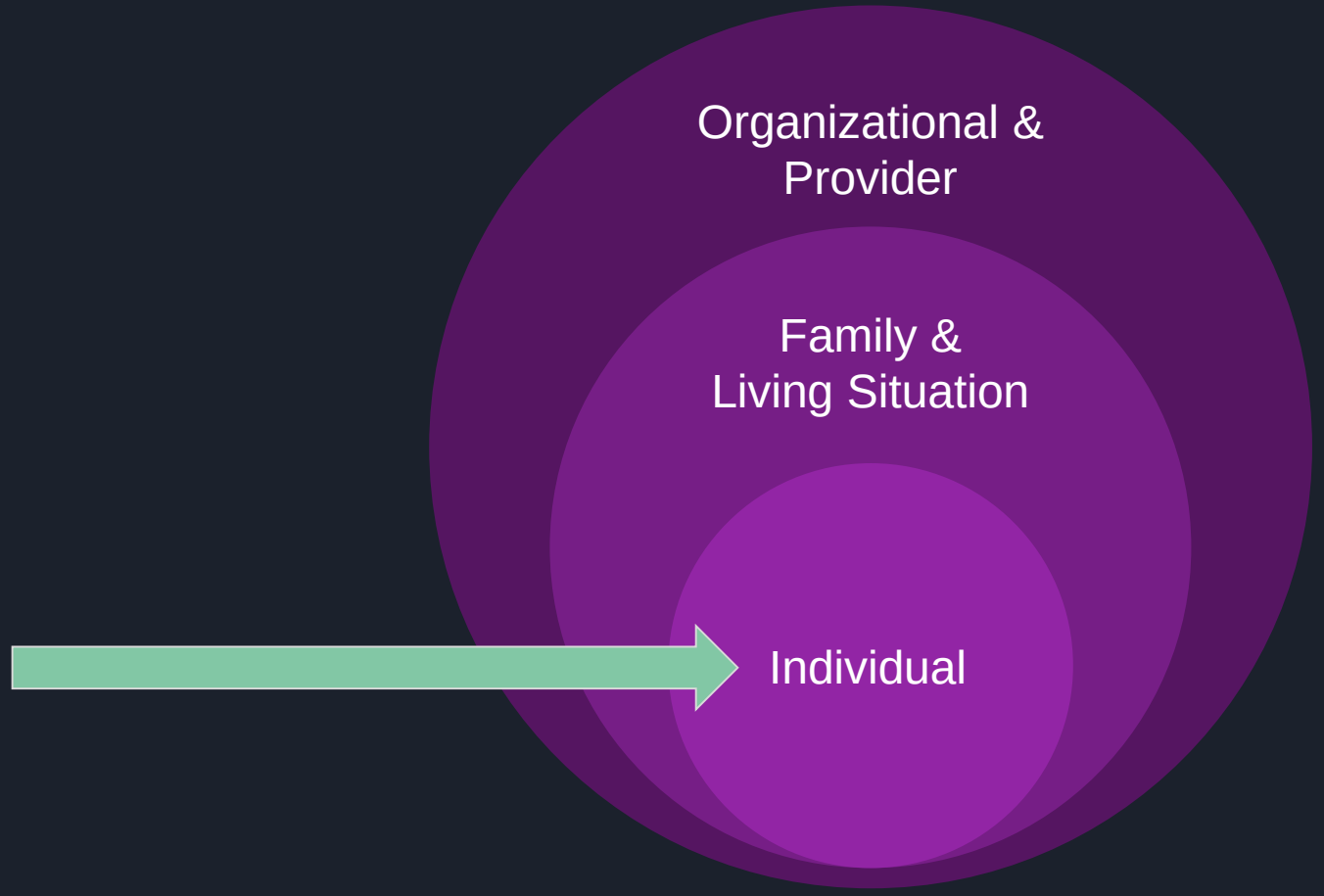
Why are women with IDD less likely to receive screenings?

- Family caregiver
  - Beliefs
  - Concerns
  - Decision Making
  - Support & information



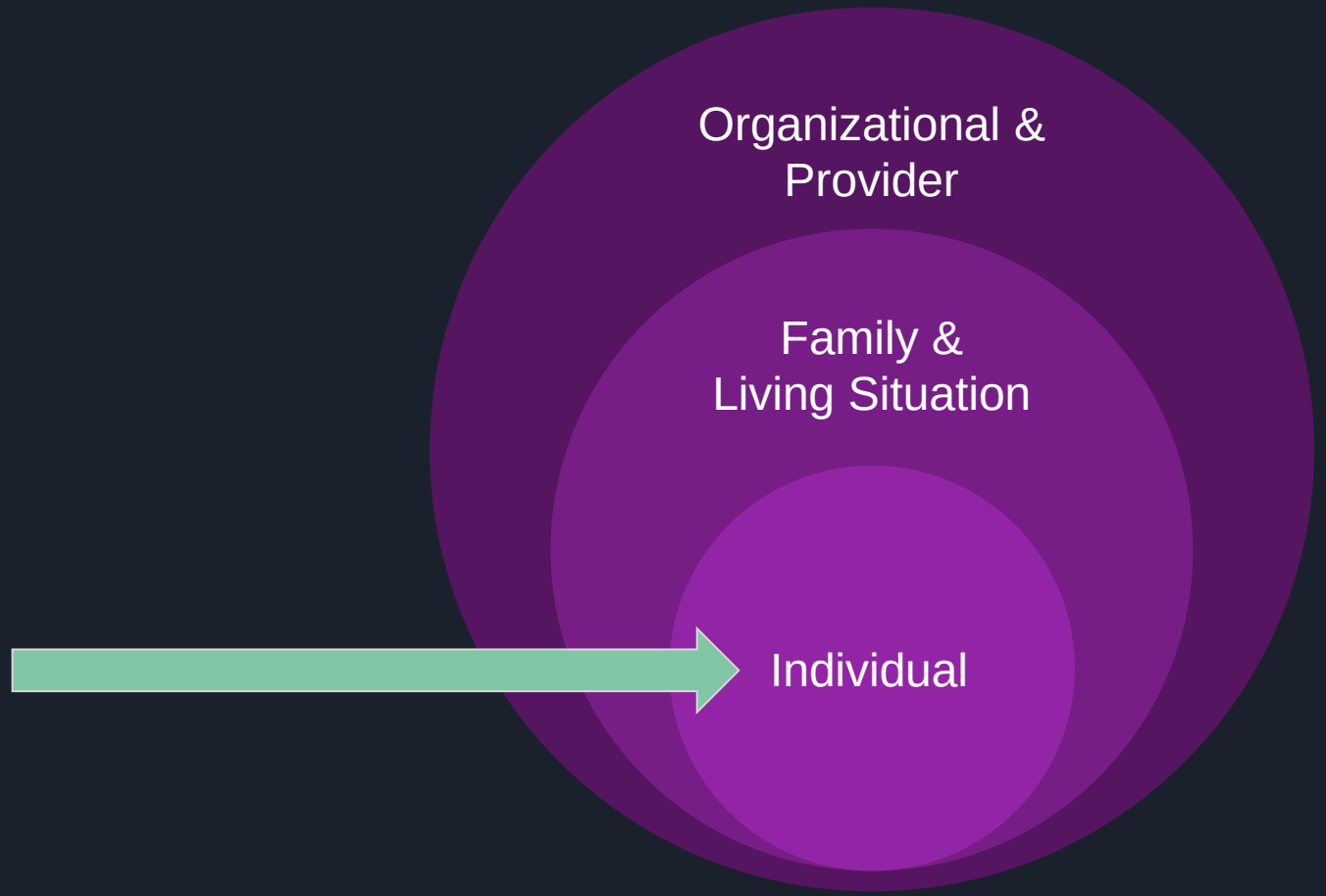
Why are women with IDD less likely to receive screenings?

- Personal characteristics:
  - Self-efficacy
  - Employment
  - Income
  - Education
  - Activity level



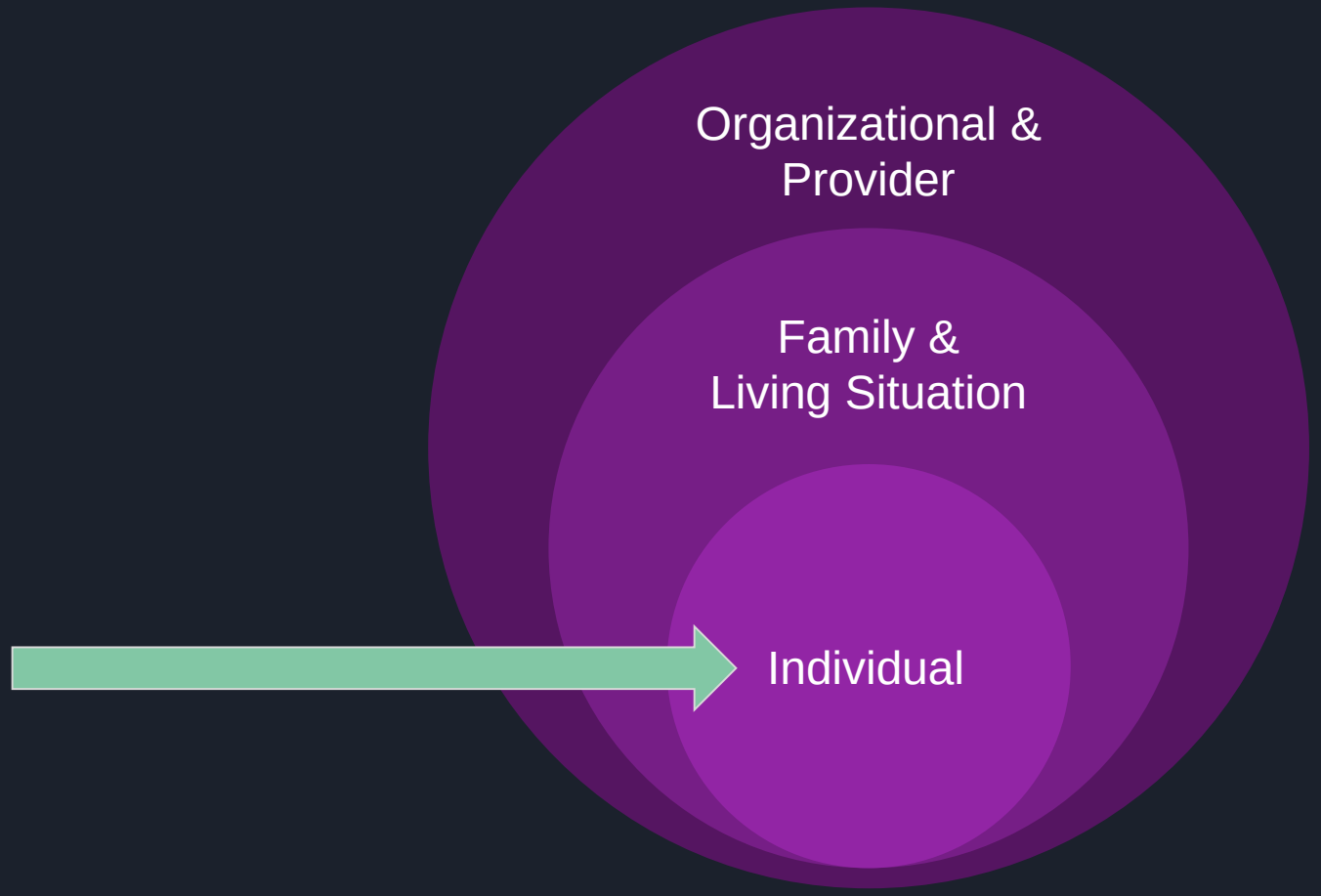
Why are women with IDD less likely to receive screenings?

- Personal characteristics:
  - Screening history
  - Knowledge about body
  - Sexual health knowledge
  - Knowledge about preventive health care



Why are women with IDD less likely to receive screenings?

- Personal characteristics:
  - Anxiety
  - Cognitive limitations
  - Sensory issues
  - Mobility

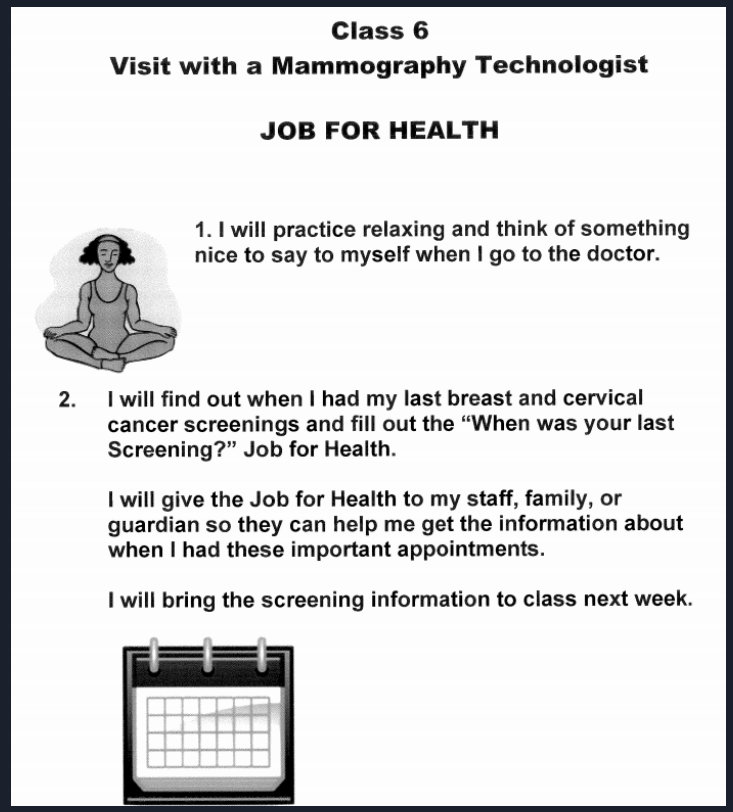


Women Be Healthy 2 (WBH2) Curriculum

- Goal to improve knowledge and use of cancer screenings for women with IDD
- Three topic areas
  - Reproductive health
  - Fear and anxiety associated with procedures
  - Self-advocacy
- Uses role playing, take home activities, relaxation techniques, hands-on exposure to screening tools

Women Be Healthy 2

- Improved knowledge among women who participated
- Implemented in urban area
- Women were either White or African American



Class 6

Visit with a Mammography Technologist

JOB FOR HEALTH

1. I will practice relaxing and think of something nice to say to myself when I go to the doctor.

2. I will find out when I had my last breast and cervical cancer screenings and fill out the "When was your last Screening?" Job for Health.

   I will give the Job for Health to my staff, family, or guardian so they can help me get the information about when I had these important appointments.

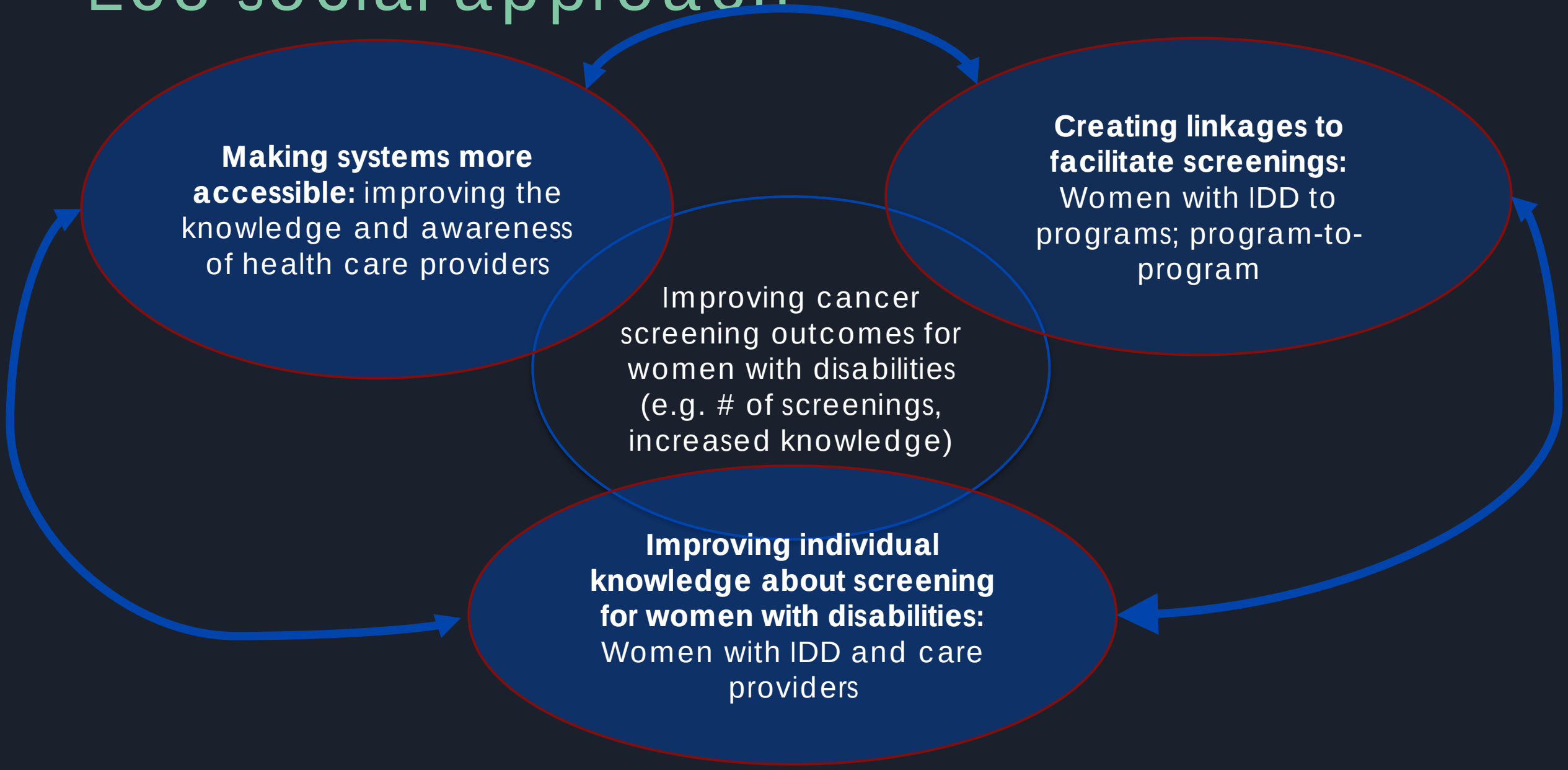
   I will bring the screening information to class next week.

Project Activities & Future Goals

Problem Statement

- Women with IDD experience disparities in cancer screenings
- Women with IDD who also identify as AI experience greater disparities in cancer screenings
- Resources exist to address cancer screenings that may not be locally or culturally relevant
- Resource focuses on women with IDD and not caregivers or providers

Eco-social approach



Questions

- What are the facilitators and barriers related to cancer screening for American Indian (AI) women experiencing intellectual and/or developmental disabilities (IDD)?
- How can we use these findings to culturally adapt an existing breast and cervical cancer education program for AI women with IDD?

Project Goals

- Build partnerships
- Assess barriers and facilitators to cancer screening in order to adapt WBH2

Project Activities - Year One
(September 2017- August 2018)

Build partnerships

- Form Advisory Board (AB)
  - Outreach
  - Research
  - Statewide context of health care for American Indian women
  - Provide feedback on existing cancer screening resources

- Identify Native organizations, tribal groups, or disability groups who would like to partner
  - Development of a research team
  - Define steps for securing tribal resolutions, tribal council approval or other approvals

Advisory Board

- Agnes Attakai (Navajo)
  - *Director of Health Disparities Outreach Prevention Education*
- Betty John (Navajo) and Catherine Puerta Palma
  - *Tribal Liaisons for Arizona DES Division of Developmental Disabilities*
- Darold Joseph (Hopi)
  - *Institute for Human Development, Northern Arizona University*
- Jon Meyers
  - *Executive Director of The Arc of Arizona*
- Kim Russell (Navajo)
  - *Executive Director of the Arizona Advisory Council on Indian Health Care*
- Virginia Warren
  - *Office Chief of Cancer Prevention and Control, ADHS*

Project Activities Year 2 (September 2018- August 2019)

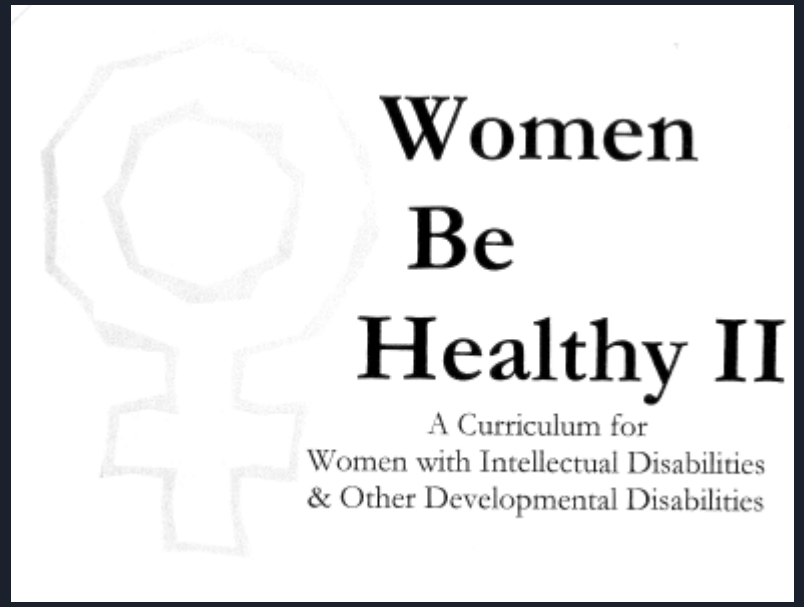
Assess barriers and facilitators to cancer screening

- Conduct in-depth interviews to explore barriers and facilitators to cancer screening (in 2 communities)
  - AI women with IDD (N=24)
  - Family caregivers (N=24)
  - Health care providers (N=24)
  - Leaders in partnering communities (N=12)

- Begin development of a sustainable and feasible cancer screening education program

Future Goals (2019 - 2022)

- Program Plans
  - Culturally adapt the Women Be Healthy II (WBH2) curriculum in partnership with two partnering organizations
  - Conduct an exploratory trial to evaluate WBH2 curriculum with AI women with IDD and their caregivers
  - Develop sustainable resources for cancer screening for all women (universal design)
- Funding Plans
  - Application to the Partnership for Native American Cancer Prevention
  - Applications to NIH and/or private foundations



Group Discussion

What was the one thing we could do to better provide cancer screenings for women with IDD?

1. Write down an idea on your note card
2. Hand your card to someone else, keep it going for a minute– Don’t read it, just keep passing. When we say stop everyone will have one card

What was the one thing we could do to better provide cancer screenings for women with IDD?

3. Read the card you have
4. Score the idea from 1 to 5 (1 being low, 5 being high) on practicality and effectiveness
5. We will repeat this process 5 times
6. Will share those with the highest scores with the group

Thank You!
Questions?

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