



Cultural Sensitivity and Community Based Health Care

by Mary Ann Foss, Joyce Saylor, Charlotte Hewitt and Maisie MacKinnon



“Because of their good work I see more older women coming in. I say ‘Gee Auntie, I am glad you’re here.’”

— Connie Fox,
Mandan/Hidatsa
Women’s Way enrollee/advocate

Women’s Way, the North Dakota Breast and Cervical Cancer Early Detection Program (BCCEDP), had already recognized the value of cultural sensitivity in reaching more American Indian (AI) women when it asked the Centers for Disease Control and Prevention (CDC) for technical assistance. CDC identified the National Indian Women’s Health Resource Center (NIWHRC) through an AI co-operative agreement designed specifically to enhance AI/AN screening in tribes and states. Historically, *Women’s Way* regularly participated in annual CDC tribal-specific outreach and other trainings. *Women’s Way* state coordinators also watched the progression of CDC’s American Indian Screening Initiative in Montana. Most significantly, *Women’s Way* was building respectful relationships and increased screening numbers at North Dakota’s four reservations and one Indian Health Service Unit site. On that premise, the question was asked, “How can we build on what has worked so far to reach even more American Indian women?”

The best approach was to include AI women and the public, tribal and Indian Health Service (IHS) health care providers who serve them. NIWHRC assisted *Women’s Way* to take two major action steps. The first was a formal needs assessment that took place during sixteen meetings at five reservations traveling over 1,500 miles. The second involved ten focus groups with AI women statewide to determine AI women’s learning styles and education needs. The results of these two reports became the basis of a culturally considerate plan of action and is a continuing work in progress.

The technical assistance approach is unique from state to state because tribes’ political, social, and traditional customs within the states are also unique. Enhancing cultural competency acknowledges tribes’ distinctions and encourages sensitive behavior proven to reduce access barriers and increase the use of women’s health screening services, particularly in American Indian communities.

The Needs Assessment Process Begins

Women's Way is required to meet the same criteria as other funded BCCED Programs. However, the approach it uses must be tailored to the unique needs and barriers to access for AI women in North Dakota. NIWHRC suggested that no one knew better what deters or encourages women to get screened for breast and cervical cancer than Indian women themselves.

Feedback and ownership

Within twelve weeks of reaching out for assistance in developing interventions that would complement *Women's Way's* initial work, a statewide needs assessment was underway. Sixteen meetings at five tribal locations took place over two weeks. Facilitators met with key Indian women, IHS staff, tribal health program staff, *Women's Way* local coordinators, outreach and state health department staff. Feedback indicated that involvement fostered a sense of partnership in the planning process and a greater degree of ownership in the program itself.

The needs assessment objectives

- ❖ Identify *Women's Way* program strengths
- ❖ Identify current and potential challenges and barriers at the program and community levels
- ❖ Identify needs at state and local levels
- ❖ Identify needs of partners (IHS, Tribal, etc.)
- ❖ Identify service gaps within AI communities
- ❖ Identify needs of community AI women
- ❖ Develop strategic plan based on needs assessment data

The findings

Recurring themes of identified needs emerged during the needs assessment meetings including,

- ❖ **At the health care provider level** – a lack of retrievable data; IHS and tribal health systems issues; targeted collaboration and strategic outreach needs; a need for more resources, e.g., staff, time, money, training and education; challenges with referral, tracking, and followup of abnormal results.
- ❖ **At the community level** – a shortage of female providers; lack of access to mammography machines; unkept appointments; fear of exams; fear of cancer; lack of culturally relevant educational material; lack of an advisory, inclusionary forum for AI women.
- ❖ **At the statewide level** – a need to strengthen partnerships; for planning and implementing systems change; for the recognition of a sustained commitment for long term success.



Figure 1: American Indians represent over five percent of North Dakota's total population of 642,200. Of the 31,329 American Indians that live in North Dakota, 59.8 percent live on reservations, while 40.2 percent live off reservations. American Indians receive Indian health care in North Dakota at four reservations and one Indian Health Service Unit.

Source: North Dakota state data center: <http://www.ndsu.nodak.edu/sdc/data/census.htm>

Community Level Focus Group Conducted

Learning the answer to how American Indian women of North Dakota best receive their health messages was identified in the needs assessment. As a result, AI women were approached at the community level—homemakers, students, retired and working women—through ten meetings at five tribal locations to learn what communication channels they use, how they prefer to receive their health information, who influences their health decisions and more.

Asking those who know best in a culturally sensitive way

Although the targeted focus group process is a scientific research method, many Indian communities respond well to it because it mirrors traditional talking circles. To follow are other culturally sensitive ways the focus groups were conducted:

- ❖ The names of key contacts in AI communities were gathered via the AI woman “network” (Indian women who know Indian women).
- ❖ Invitations were hand signed and addressed. Women later reported that they felt pleased to be personally invited to help structure access to services for others like themselves.
- ❖ Meetings began with invocations by key Indian women leaders. They ended with small giveaways such as sweet grass braids, ceremonial tobacco and so on.
- ❖ AI women lead the focus groups.

“ There a lot of presumptions in health care. You can’t fix any barriers until you know what the barriers really are. ”

— Dr. Jackie Quisno, M.D.,
GrosVentre

Clinical Director, Standing Rock IHS Hospital
Women’s Way Medical Advisory Board Member

Styles of learning	Channels of communication	Findings
Listening & Conversations	Radio Individual Counseling Organized Groups Informal Conversations	Approx. 50% prefer listening and conversation as a way of learning
Reading	Magazines - women’s Newspapers - local/free Brochures - rarely Internet - health sites Direct Mail - from identifiable sources	Approx. 25% prefer this way of learning
Visual	Television Videos	Not often for health information

Figure 2: At least half the women participating in the focus group preferred to get their information through conversation, which allows them to assess the person who is speaking and decide whether they are knowledgeable and can be trusted.

Barriers, Knowledge, Attitudes and Beliefs

In addition to what channels of communication they prefer to receive their health information, women were also asked to identify barriers to accessing and receiving women’s health services. The barriers they identified were divided into two categories: 1) structural barriers; and 2) knowledge, attitudes and beliefs about health care. For the most part structural barriers, such as the distance to travel to a mammography unit or physician turnover, are not susceptible to correction through consumer health education. However, issues relating to knowledge, attitudes and beliefs can be addressed through health education messages.



“ If you look at the *Women’s Way* focus group report you see that American Indian women want to receive messages from respected people in their community. ”

— Dr. Terry Dwelle, M.D.
North Dakota State Health Officer

Type of Barrier	Examples
Cultural Values	<ul style="list-style-type: none"> ● Embarrassed to have male provider do exam ● Invasion of privacy ● Prohibitions against talking with men (e.g. son-in-law) ● Inadequate communication, coordination or referrals between traditional healers and Western doctors
Lack of Information	<ul style="list-style-type: none"> ● Women don’t know why mammograms are needed ● Don’t know consequences of not getting tested ● “We need to know our family histories” ● “Too old for Pap test” ● “Married to the same person for a long time so I don’t need it”
Fear	<ul style="list-style-type: none"> ● Afraid to be diagnosed with cancer ● Afraid of costs associated with treatment ● Fear that the whole bill may not be paid ● Mammograms hurt ● Other tribal members work in the clinic, perception is that information is not confidential ● Clinic walls “are paper thin”
Denial	<ul style="list-style-type: none"> ● To not know is better than to know ● “It won’t happen to me”

Figure 3: Excerpted findings from the focus group report entitled, *The Learning Styles, Channels of Communication, and Knowledge of Women’s Health Services Among American Indian Women in North Dakota.*

Sharing the results

Application of the focus group exceeded its original expectation to help improve screening numbers for AI women. The findings on the barriers to health care access for AI women, including behaviors, health systems issues, cultural values, etc., were presented to North Dakota State Health Officer, Dr. Terry Dwelle, and approximately sixty other state health department program staff at the state capital. In addition to diabetes, tobacco and family planning public health programs, the report is being shared with private, state and public colleges. Dr. Dwelle also incorporated what was learned into a “Cultural Communications Brown Bag Lunch” series for state health department staff and a lecture series for the University of Minnesota Public Health Cultural Competency curricula. A summary was also presented by NIWHRC consultants at the annual Dakota Conference on Rural and Public Health. *Women’s Way* local coordinators were presented with the needs assessment report at a quarterly meeting.

Applying What Was Learned

Local coordinators are responsible for finding and enrolling new women into the program, maintaining screening data records, and reminding women to re-screen. They also conduct health education and ensure that women receive adequate follow-up and treatment.

Within weeks of participating in the needs assessment, the state committed to using the recommendations by NIWHRC and the participants to structure *Women's Way* at the local levels. Examples of the proven practices to enhance screening outcomes that the local coordinators began, or continued using, include the following:

- ❖ **Hand addressed reminders**—AI women said they read personalized letters, so several local coordinators are using hand addressed pink envelopes to remind women to re-screen.
- ❖ **Tribal talk radio**—Fifty percent of the women asked said that listening was a preferred way to learn about health care. As a result, one local coordinator invited a tribal woman to lead two discussions on tribal talk radio.
- ❖ **Talking circles**—A local coordinator held talking circles for women to discuss health issues in a confidential environment.
- ❖ **“Women’s Health” days**—More women’s health days are being held that include health education and specific *Women’s Way* services. Local coordinators also offer individualized instructions on breast self-exams (BSEs).
- ❖ **Female providers**—The female physician at the Standing Rock IHS clinic agreed to do clinical breast exams (CBEs), Pap tests and annual exams for women on “Women’s Health” days. Female providers from other clinics have assisted with exams at Spirit Lake and other clinics during their special events, as well.
- ❖ **Networking**—Local coordinators are seeking collaborative program sponsors, such as the Avon Foundation Breast Care Fund and local businesses, to help with thank you gifts and incentives.
- ❖ **One-to-one communication**—Community Health Representatives (CHRs) have proven to be a powerful supportive voice for the program. Tribal Health educators are also being asked to spread the word about *Women’s Way*. In addition, enrolled women are encouraged to share their values for health care with other AI women.
- ❖ **Culturally relevant health material**—To support all of the local coordinators in their recruitment efforts, the state staff created a health education poster and a *Women’s Way* brochure exclusively with North Dakota Indian women’s faces and other easily identifiable American Indian images.



“My local coordinator is a pest in a good way. Some pests I would swat at, but not her.”

— Gladys Hawk
Standing Rock Sioux Tribe
former *Women’s Way* enrollee
and Breast Cancer Survivor

A Commitment to Follow Through

Continuing the good work

A significant outcome of the lessons learned from the two reports included developing short term and long term plans. The goal is to support an ongoing process whereby the number of AI women screened for services will continue to increase. The commitment to implementing the short term planning phase included the following:

Commitment to AI women

- ❖ **The hiring of American Indian Screening Initiative (AISI) Coordinator**—As human resources, time and funding remain available, the AISI Coordinator will assist in completing the long term plan, and will facilitate greater involvement of IHS Units, Tribal Health and private providers.
- ❖ **Annual AI women advisory meetings**—A plan is in process to develop local talking circles at each tribe that will designate a representative to speak on American Indian women's health issues at a state meeting each year.



Graphic Design by Kim Cowden

Figure 4: *Women's Way* and the Avon Foundation Breast Care Fund developed a breast self-exam brochure for the Standing Rock Sioux Tribe early in the *Women's Way* program. Soon after the needs assessment and focus group results, *Women's Way* developed several other culturally sensitive education materials.

“ I was happy to give a lot of information to them. Still, I always ask. ‘Am I going to see something I can trust?’ ”

— Elaine Keepseagle
Standing Rock Sioux Tribe
CHR Program Assistant
Women's Way enrollee/advocate

Commitment to education and training

- ❖ **On-site and video conference Cancer 101 trainings**—An American Indian woman physician conducted trainings at six sites over two weeks to CHRs, program volunteers and advocates, and to state health department staff.

- ❖ **Cultural Competency training**— AI women presented information to over one hundred people in Bismarck, on AI family values, traditional health practices, spiritual beliefs, treaty based obligations for Indian health, and issues of Historical Trauma Response.

Commitment to culturally relevant health messages

- ❖ **Education materials**— Traditional North Dakota American Indian images and the faces of North Dakota AI women on breast exam brochures, posters, newsletter articles, enrollment and reminder cards, etc.

Outcomes Achieved

Qualitative outcomes are being measured by the progress made using stated goals, objectives, action steps and recommendations garnered from evaluation forms. Recorded comments of participants in the needs assessment and the focus groups, and subsequent trainings and presentations also provided further opportunity for assessment. The successes *Women's Way* has achieved through its partnership with NIWHRC include the following:

- ❖ **A list of key AI women**, including respected elders in the communities, was developed and is available as a future contact list.
- ❖ **Partnerships were developed** with numerous private, tribal and federal organizations, other state health departments and private businesses.
- ❖ **An American Indian Screening Initiative Coordinator** was hired.
- ❖ **Trainings** took place that enhanced the knowledge and experience of tribal members, health care professionals and *Women's Way* volunteers and staff.

- ❖ **A plan** for short term tasks and long term objectives was created to address priorities identified in the needs assessment report.
- ❖ **Communication and trust** were strengthened between state staff, tribal health care professionals and AI women.
- ❖ **Valuable information was gained** that is useful to enhancing *Women's Way*, but also to other AI health programs in North Dakota including tobacco cessation, diabetes programs and more.
- ❖ **A better understanding** of the culture and traditions of North Dakota's primary diverse population was gained through observance, interaction and education.

Quantitative outcomes

- ❖ Screening among eligible AI women increased from 9.8 percent to 11.8 percent between 2000 and 2004. The highest numbers (13.4) occurred during a period of special AI women's screening events.

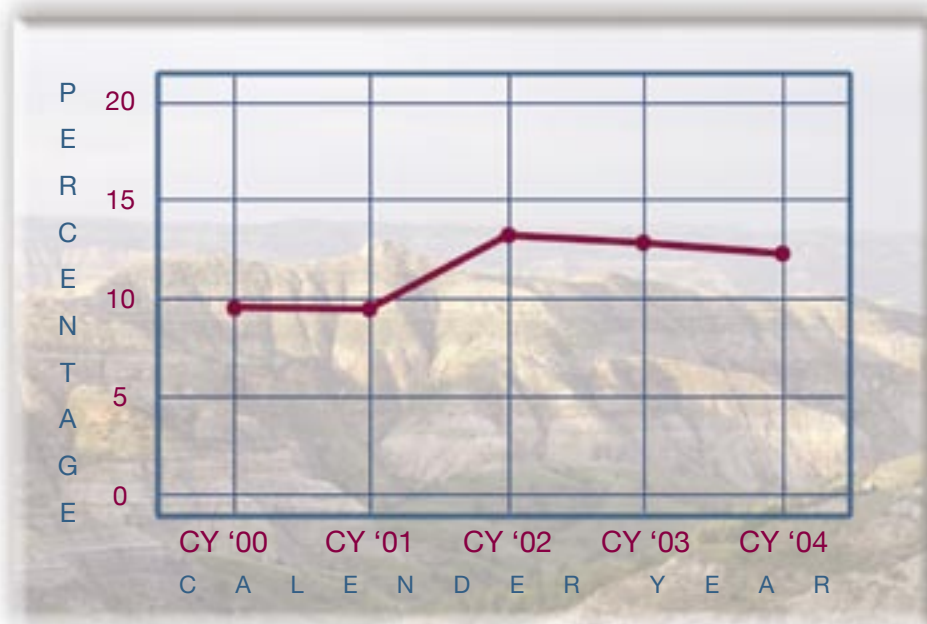


Figure 5: Qualitative outcomes are tracked by *Women's Way* CaST data system and IHS's Resource and Patient Management System (RPMS).

The Value of Partnerships

Like all works in progress, there is still room for expanding the network of support for *Women's Way*. Developing partnerships with AI women takes time. However, *Women's Way* is committed to building relationships through sincere respect for AI communities and their cultures, and by keeping AI women involved. Continued efforts to work with health systems will also promote positive outcomes for AI women, tribal health and IHS.

The list of partners helping to address barriers to screening AI women for breast and cervical cancer in North Dakota include the following:

- ❖ **Women's Way** (North Dakota Department of Health and local public health agencies)
- ❖ **Women's Way volunteers**
- ❖ **Key American Indian women** who support and advocate for *Women's Way*
- ❖ **Those IHS Units/facilities** that help recruit women and that provide health care providers
- ❖ **Tribal Health**
- ❖ **Tribal Councils** – E.g., tribal resolutions encouraging health care, tagging onto the tribe's health conferences, etc.
- ❖ **Women's Way Medical Advisory Board**
- ❖ **The Office of the First Lady, Mikey L. Hoeven**, advocates for *Women's Way* in her travels around the state. The First Lady is featured on the *Women's Way* 'Aware and Alive' video
- ❖ **North Dakotans Partnering for Women's Health** is an active collaborative partnership involving many organizations from around the state
- ❖ **National Indian Women's Health Resource Center**
- ❖ **American Cancer Society and the Reach to Recovery program**. Supplies, resources for treatment, prosthetics, and one-on-one support and information to *Women's Way* clients
- ❖ **North Dakota Indian Affairs Commission**, a resource for culturally appropriate feedback on plans and activities
- ❖ **North Dakota Family Planning**
- ❖ **Private providers** who also recruit and provide health care providers for AI women
- ❖ **Local businesses and organizations** that provide incentives and thank you gifts and that help promote screening events
- ❖ **Centers for Disease Control and Prevention Breast and Cervical Cancer Early Detection Program, Division of Cancer Prevention and Control**

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