



Organizing for Advocacy and Access in Northeast Kansas



An unprecedented integration of health care for American Indian (AI) women is taking place between the state of Kansas and its four Native American tribes. Formerly insular health care systems, the partnerships now involve sharing respective resources and unique expertise to expand cancer diagnosis and treatment for all uninsured AI women living on or off the reservation. While the main objective is being realized, more women are being screened, significant accomplishments have occurred as a means to that end. For example,

- ❖ **The Four Tribes Women's Wellness Coalition (FTWWC)** – This grassroots, non-profit, health advocacy group began at a residence on the Kickapoo reservation. Now tribal members from the Iowa Nation, Prairie Band Potawatomi Nation, Sac and Fox, and the Kickapoo Tribes make up a board of directors responsible for an essential communication link among the state and the four tribes in northeast Kansas.
- ❖ **The Iowa Nation, Prairie Band Potawatomi Nation, Sac and Fox, and the Kickapoo Tribes** – All four tribes authorized the state to conduct a first-time health survey for their respective reservation based AIs. In addition, each tribe has supported the FTWWC with food, meeting rooms, furniture, equipment and other donations. Also, the Prairie Band Potawatomi Health Center has become the first *Early Detection Works*–contracted provider at a tribe in the state.
- ❖ **The Kansas Department of Health and Environment's (KDHE) Early Detection Works (EDW) Program** – After identifying the need, KDHE took deliberate action to reverse the lack of AI enrolled women in the *Early Detection Works* Breast and Cervical Cancer Early Detection Program. Help was solicited from AI women leaders and the ensuing support to the FTWWC was critical to the group's efficacy. Continued resource sharing directly to the tribes through the *Early Detection Works* program has led to enhanced access to cancer diagnosis and treatment for all AI women regardless of where they are seen. This and other resources, from health education literature to data collection, continue to help the tribes and the FTWWC serve their own communities.

Clearly, every point in the triadic partnership made possible every other relationship. Without the staff and funding investment by the state on one hand, and the critical support of the tribal governments and tribal clinics on the other—made possible by the women from their own communities—the health survey, increased *Early Detection Works* enrollment, and the first tribal *Early Detection Works*–contracted provider in Kansas would still be envisioned goals, and not significant outcomes.

The State: Recognition, Reliance and Results

The growing relationship between KDHE's *Early Detection Works* program, and the four Kansas tribal health care systems began with a simple inquiry—and a commitment by the state to address a recognized need.

A woman telephoned the KDHE's Cancer Prevention and Control director and wanted to know, as an American Indian woman, could she enroll in the state's *Early Detection Works* program? New to the state position, the director made a call to the Centers for Disease Control and Prevention (CDC) program consultant. She learned the answer was an emphatic, "yes." AI women who meet the same eligibility requirements as all women are encouraged to enroll in state programs. The director inquired further and learned that the data at that time showed, 1) that there were only twenty-one identified AI women enrolled in the *Early Detection Works* program and 2) there were no *Early Detection Works*-contracted providers in northeast Kansas, where all four tribes are located.

Thus began a concerted effort by the state to reach under-served AI women. However, a year later, in 2003, efforts still resulted in no significant increases in enrollment for AI women and no *Early Detection Works*-contracted providers in the area. The state decided to follow the example of other state and tribal collaborations and ask AI women themselves for help and leadership.

In short time, several AI women responded by organizing the Four Tribes Women's Wellness Coalition (FTWWC). The non-profit, grassroots group relies on resources offered by the state, the tribes, small grants, and most importantly, from AI women volunteers.

The state collaborates with the FTWWC, the tribes, and subsequently, low-income AI women, as follows:

- ❖ The state cancer director has attended FTWWC coalition meetings to help brainstorm ways to improve health education, and provides technical assistance when needed,
- ❖ acted as the umbrella fiscal agent while the FTWWC coalition prepared its 501(c)3 application,
- ❖ funds the coalition's outreach worker, and provides educational literature,



“ This is working well maybe because we are aware of, historically, how many times promises have been broken. ”

— Janet Neff

Director, Kansas Department of Health and Education: Cancer Prevention and Control

- ❖ provided staff, funding, technical assistance and gas cards as incentives for a first-ever tribal-specific health survey; did the survey data entry, and provided staff for the data presentation,
- ❖ provided technical staff and the web-hosting service for the coalition's web site,
- ❖ provides a state-wide, toll-free, telephone-based central *Early Detection Works* enrollment system, alleviating the task of qualifying and enrolling women from tribal clinic staff, and
- ❖ provided the coalition with the names of health service providers (oncologists, surgeons, etc.) who were already familiar with Breast and Cervical Early Detection Program (BCCEDP) services and billing systems. This helped the Prairie Band Potawatomi establish the subcontracting relationships necessary to become an *Early Detection Works*-contracted provider.

Four Tribes Women's Wellness Coalition

The Native voice of health advocacy for American Indian women in N.E. Kansas

It was clear: the best way to expand the personnel and service resources available to the tribes was to include AI women in the process itself. That led the state to ask the only American Indian woman physician on the Kansas cancer advisory board for help. The physician, a former clinical director at Haskell IHS Health Center and a member of the Iowa Tribe, met with other key American Indian women and the Four Tribes Women's Wellness Coalition (FTWWC) began.

Grassroots without so much as a desk

Respected women from the Iowa, Prairie Band Potawatomi, Sac and Fox, and Kickapoo Tribes meet once a month to plan effective ways to offer health education and to address barriers to access and treatment. Their expertise—and the innate knowledge they possess about their own communities—is vital. Members include medical professionals, a social worker, tribal officials, and cancer survivors.

Little money, no office space, no office furniture, no paid staff and few resources did not deter the grassroots group from realizing ambitious goals. By offering a community service not otherwise available at the state and tribes, and communicating clearly what were their needs, resources were made available. Examples include,

- ❖ **The state** pays the salary and provides training for a part-time coalition outreach worker; provides education literature; technical support with the web site; funding to implement the health survey, as well as the staff for data entry and evaluation; and networking for key contacts and resources.
- ❖ **The tribes** – Coalition members are able to connect with established relationships from all four tribes for valuable resources including meeting spaces, office space, food, furniture, computer equipment and cash donations.
- ❖ **National Indian Women's Health Resource Center (NIWHRC)** provided technical assistance for strategic planning, health education materials, training, etc. NIWHRC's own consultant, a native woman, lives in northeast Kansas, and has a local perspective on the needs of AI women. This makes NIWHRC's support especially accessible and effective.



“ It is important to accommodate women for things like mobility and distance. If not, they will just stay home. ”

— Joann Comer,
Iowa Tribal Council Member and FTWWC
Board member

Setting up for the long-haul

A commitment to the future means dealing with the endless details of setting up a solid organizational foundation—without detracting from the mission of reaching AI women. Accomplishments include,

- ❖ **Health education** in a culturally appropriate way, at tribal health fairs, pow wows and other planned activities such as women's conferences, and most effectively, through casual, one-on-one exchange.
- ❖ **A three year plan** – Less than nine months after its inception, the group developed a strategic plan. Visions for the future include helping to remove the fear of cancer as a death sentence, and, as a longer range plan, having annual mobile mammography units at each tribal clinic.
- ❖ **Grant awards** – Proposals written by the coalition board and funded by the Spirit of Eagles, the Sunflower Foundation, each of the Kansas tribes, the Office on Women's Health, Susan G. Komen Foundation and others, help to fund the executive director position, office space and community education events.
- ❖ **Preparing a 501(c)3 application** and completing other board administrative duties such as by-laws, personnel policies, accounting, insurance, etc.

The Tribes: Identifying and Prioritizing Needs

Placing health care in line with other priorities is no easy task. Competing issues encumber large and small tribes alike—especially since they are confronted with the same responsibilities as other government entities: employment, housing, elder services, child welfare, roads, schools and more. Gaining access to tribal officials who have many community priorities takes time, patience and persistence.

Fortunately, in northeast Kansas, the women from the FTWWC are familiar with their tribal council members or other key personnel, and they are acquainted with tribal protocol. They are also willing to travel long distances between the tribes and the state offices as often as necessary. This can mean picking up health education material from the state for a presentation at one of the tribes, or hand delivering formal letters to 24 tribal council members. With persistent advocacy by those who stand to gain the most, that is AI women, integrating the *Early Detection Works* program into the tribal health care systems has begun. In the first 24 months of the coalition's existence each of the four tribes,

- ❖ authorized the state to conduct a health survey through a formally negotiated Memorandum of Agreement,
- ❖ supported the FTWWC with meeting spaces, food, funding for health education events, a temporary office, furniture, computer equipment, etc.,
- ❖ sanctioned the on-going discussions with tribal health administrators, about the *Early Detection Works* program, and other women's health issues,
- ❖ invited the group to do educational presentations at community events such as tribal health fairs, senior center lunches and employee staff meetings,
- ❖ and, as in the case of the Prairie Band Potawatomi, secured the medical service subcontracting relationships needed to become an *Early Detection Works*-contracted provider.

Infrastructure in flux

At the same time that the state was asking the tribes to consider incorporating the *Early Detection Works*

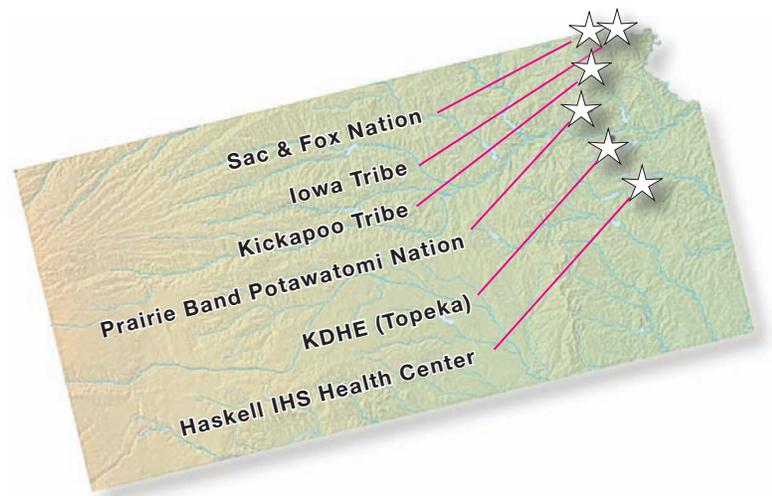


Figure 1: Reservation-based health care is comprised of the Indian Health Service (IHS) Kansas Service Unit. This includes one IHS health facility at the Iowa Tribe (the White Cloud Health Station), two self-governing tribal compact health centers at the Kickapoo Nation, Prairie Band Potawatomi Nation, and the Haskell Health Center in Lawrence. Tribal Members from the Sac & Fox Tribe can be seen at any one of the clinics. The Kansas Department of Health and Environment (KDHE) is located at the state capital in Topeka.

program into their health systems, the tribal clinics had several, high-priority, administrative issues going on. Without the FTWWC serving as cultural liaisons, the tribes might have appeared uninterested in the program when in fact, they were involved with pressing governmental issues or were developing the necessary infrastructure to better serve their patients. Examples include,

- ❖ **The Kickapoo Tribal Clinic** experienced a vacancy in their practitioner position for several months in 2006. This is not an uncommon issue to rural tribes who must find qualified medical staff willing to travel long distances—or relocate to isolated regions.
- ❖ **The Prairie Band Potawatomi** – Two years was dedicated to planning and building a multi-complex health center that opened in November 2006. Details included hiring staff, setting up an improved billing and collection process, and putting into place three additional departments including a dental clinic, behavioral health and on-site radiology. In August 2007, the clinic became an *Early Detection Works*-contracted provider.

The Early Detection Works Program

Utilizing state resources; gaining reimbursement for breast and cervical services; and providing local care for low-income women living on or off the reservation

Adding the *Early Detection Works* BCCEDP as another data tracking and third-party billing procedure can seem daunting to tribes. However, with the assistance of the state to help complete the necessary data and paperwork forms, the state and tribes are more easily navigating through the common ground in which each does business.

The system of health care can vary from tribe to tribe. However, as an *Early Detection Works*-contracted provider, the process of reimbursement is the same.

When a tribal clinic is an *Early Detection Works*-contracted provider

To become a contracted provider, a clinic has to have patient-provider subcontractors for any phase of service it cannot itself provide. Once accomplished, the tribal or IHS clinic may bill the state for qualifying services the same way it would any third-party billing (e.g., Medicaid or private insurance). This is true whether the exams have normal or abnormal results.

The gains are,

- ❖ The clinic is reimbursed for services it may have normally offered an uninsured woman, meaning the service is no longer an expenditure in the operating or Contract Health Service (CHS) budget.
- ❖ The clinic may request reimbursement for any *Early Detection Works*-enrolled, uninsured, low income woman—whether she is a tribal member of that tribe, or lives inside or outside the reservation.

For women with abnormal results,

- ❖ An *Early Detection Works*-contracted provider clinic can refer any woman enrolled in the program to one of its local, patient-provider sub-contractors at a nearby hospital or specialty care clinic.
- ❖ The woman does not need to live on the reservation to receive local services.
- ❖ Payment is not dependent on whether the patient is a tribally enrolled AI woman, or again, whether she lives on the reservation.

“It’s a win-win-win for everyone. Eligible women are seen at their regular clinics where they are comfortable, and if they have a breast or cervical problem, all their referral care is covered, even if they are not CHS eligible; the clinic gets reimbursed for every EDW-enrolled woman they provide care for; and the clinic does not have to use its CHS dollars for women referred for further EDW diagnosis or treatment.”

— Dr. Dee Ann DeRoin
Iowa
FTWWC Board President

- ❖ Tribal Contract Health Service (CHS) dollars are not used to pay for off-clinic services, leaving them available for other prioritized health needs. This is especially important if priority cases have exhausted the CHS funds for that year. If the clinic were not a contracted provider, and the woman lived outside the reservation boundaries, she would have had to drive long distances to the nearest IHS facility where there are the appropriate services available on-site. For AI women in northeast Kansas, this means driving as far as 270 miles, (or 5 hours each way) to Claremore Indian Health Service Hospital, in Oklahoma.
- ❖ Most importantly, in all cases, an *Early Detection Works*-enrolled woman will receive the services she needs quickly, locally, at no cost to her, and with the close support of family and tribal community.

Keeping a Clear Focus

Healthy American Indian women are at the center of the efforts to provide access to breast and cervical screening between the four Kansas tribes, the State of Kansas, and the Four Tribes Women's Wellness Coalition.

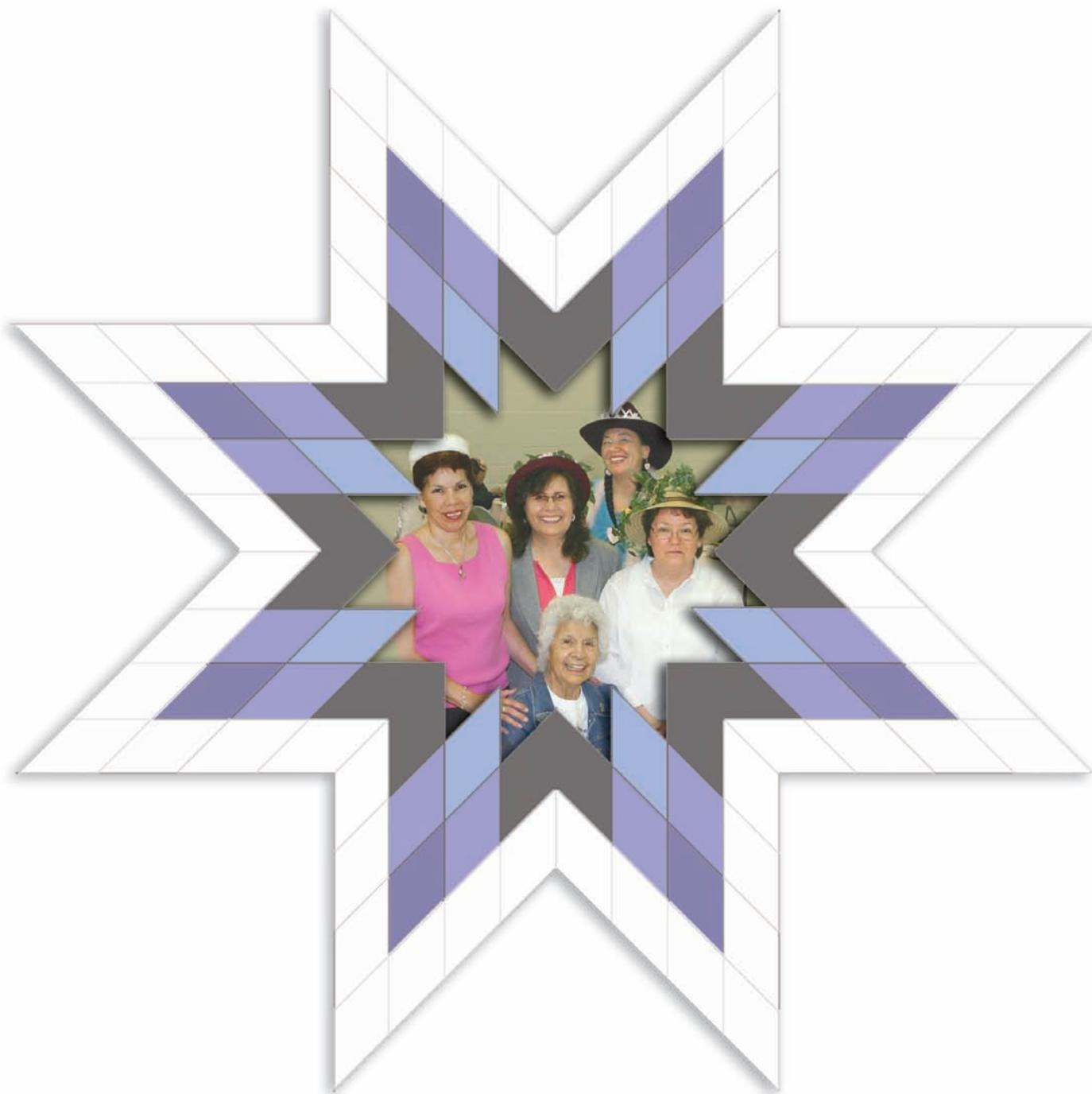


Figure 2: The FTWWC sponsored a “crazy hat” contest during a health education tea party. The event drew women from all four tribes. Pictured (L to R) are, Denise Chavez, Gaile Reed, Theda NewBreast, Nina Merchant; (front) Iowa Tribe Tribal Council Member and FTWWC board member, Joann Comer.

The Tribal Health Survey: Respecting Tribal Protocol

The expedient process to plan, field test, gain approval for, implement, evaluate and present the health survey, is a valuable model for any partnership process

The setting was unprecedented in Kansas: 1) A first ever health survey developed for reservation-based AIs, 2) sponsored and evaluated by the state, 3) sanctioned by the tribes, 4) enthusiastically participated in by tribal members, 5) and conducted on tribal lands during general council meetings.

Though the outcome was a collaboration among all the partners, the tribal health survey was an expressed need at the FTWWC's first meeting just eighteen months earlier. KDHE responded by providing the technical assistance to develop questions designed to solicit meaningful information for tribes and the state. Topics included perceived physical health status, health care access, diabetes, cardiovascular issues, tobacco use, etc.

Tribal involvement means tribal investment

Members from the FTWWC requested permission to do the survey by making a presentation and giving a sample of the survey to each of the four tribal councils. Tribes reciprocated by,

- ❖ granting permission to conduct the survey at general council meetings,
- ❖ mailing announcements out to their members,
- ❖ establishing Memoranda of Understandings with the state setting such parameters as how the information could be handled, what could be presented back to the communities, etc.

Government-to-government respect

Especially important to tribal and state relations was the way in which the data was presented. Earlier agreements were kept: the tribes would be in control of their own information; data from all four tribes were pooled and analyzed; summary tables featuring relevant health indicators and frequency tables for each variable were prepared and distributed; each tribe received a customized report showing their own results; Individual tribe reports were not shared with the others; nothing would be presented or published without each tribe's permission. In fact, the only people that attended the data overview session were tribal council members and key staff, the Secretary of KDHE and

“ We knew the first thing we had to do was find out what are the cancer needs of our tribes. ”

— Carol Shopteese,
Prairie Band Potawatomi
FTWWC Board Member

key staff, and the FTWWC Board. The state also offered to develop future reports for the tribes tailored to their areas of interest and their target audience(s).

The overview presentation covered the following topics:

- ❖ A discussion of data problems in Indian communities,
- ❖ The survey as a starting point for surveillance, baseline and trends,
- ❖ Data uses including planning, documentation of needs and health disparities, justifications for services and funding, indicators/measurements of progress, documentation of improvements, etc.,
- ❖ An overview of the survey participants including a comparison to Kansas all races, when possible,
- ❖ Data highlights including aggregated numbers for mental health status, diabetes, heart disease, three kinds of cancers, etc.,
- ❖ A recommendation was also made to do a more complete adult survey in each tribal community.

The data was limited to only those who attended the council meetings. Nonetheless, the survey proved valuable in establishing a baseline for AI people in northeast Kansas. It also provided the opportunity to do business with partners that had not formerly interacted. Furthermore, it helped to build trust, coordinate the implementation of a major undertaking, and establish good will between state and tribal governments.

Setting High Standards for the Future

Integrating a new specialty care program takes time and perseverance. Still, the Prairie Band Potawatomi health clinic stayed the course, becoming the first **Early Detection Works**—contracted provider at a tribal clinic in the state. Within weeks after all the paperwork was signed, a women’s day clinic for annual exams and mammogram referrals was planned.

For this and future women’s events at all of the AI health care clinics, the FTW/WC will help to recruit women. However, the Prairie Band Potawatomi health clinic also has its own recruitment plans. A software reporting system is already in place to identify uninsured women for Medicaid. The same will be used to find potentially eligible women for the **Early Detection Works** program. And, in addition to the managed care team, the registration staff will be well educated about the enrollment criteria and process.

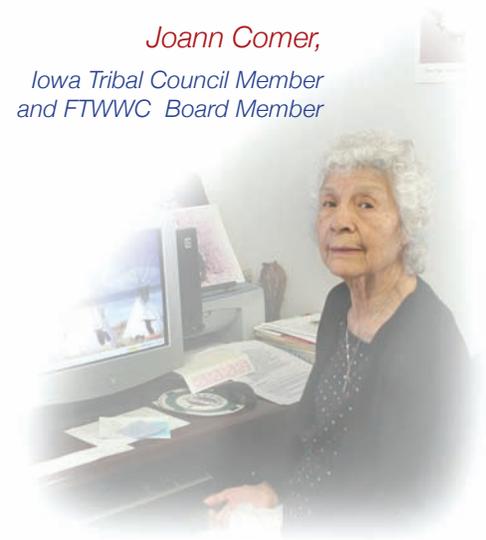
Cohesive collaboration requires constant attention. There is always more phone calls, meetings, paperwork and planning to do as infrastructure develops and partnerships build between the state, the FTW/WC and the tribes. For example, more complete data is needed to fully address health disparity issues. More women need to learn the importance of early detection. More health facilities need to become providers in order to serve their own, familiar, populations. Still, a significant foundation has been laid. The collaboration required to realize the first tribal **Early Detection Works**—contracted provider, and to increase the number of AI women enrolled in the **Early Detection Works** program has already set a respectful tone and solid direction for the good work that lies ahead.

“ The most important thing about the Native community is advocacy. If [the coalition] hadn’t intervened, we’d still be mired in quick sand. ”

— John Holtz, FACHE, MBA
Clinic Director
Prairie Band Potawatomi Health Clinic



Joann Comer,
Iowa Tribal Council Member
and FTWWC Board Member



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