Celebrating the “Diabetes Talking Circles”

How one woman’s vision provided a successful model for health practitioners and educators and improved the health for Native Americans and Alaskan Native People affected by Type 2 Diabetes.

The Creation

Lorelei DeCora is a proud Native American and an enrolled member of the Winnebago Tribe of Nebraska, Thunder Bird Clan. Through her mother, she is related to the Minnecojou Lakota Sioux. Her Indian name is Ta Wigmu Iyoyampa Win, “Her Rainbow Is Always Bright”. She is the founder of the Porcupine Clinic on the Pine Ridge Reservation in South Dakota, a Native American activist and community leader, a registered nurse, public health nurse, and recipient of the 1993 Robert Wood Johnson Foundation Community Health Leadership Award. Through her extensive health career she witnessed first hand the devastating effects of type 2 diabetes in Native American populations.

In her early years as a registered nurse, she observed that the mainstream clinical approach, in use at the time, was not as effective as it could be in preventing and treating this disease in Native American communities. She found that, for example, the approach focused on the individual rather than supportive group settings and relied heavily on one-dimensional pamphlets.

For Lorelei, a new solution was needed that drew on “who we are as a people- our life ways, merged with the science of diabetes and encompassing our spirit and emotions.”

The Spirit of “Talking Circles”

While growing up on the Winnebago reservation, Lorelei remembers seeing “talking circles,” groups in which tribal members came together to discuss community problems and issues.

“It was a way to problem solve, share a meal, and pray.”
Within the group circle, a traditional Native American item such as a feather or stone was passed around, giving the person holding the item the freedom to speak uninterrupted. The speaker was able to talk about what was on their mind or in their heart, while the group would intently listen until they were finished. Each speaker was not limited to the topic at hand and the circle could go around several times to ensure that everyone was able to express their thoughts.

The talking circles demonstrate the Native American view of the interconnectedness of life, the balance in the natural world, and the cycle of life and death. Most tribes embrace an oral rather than a written tradition and share tribal lessons of history, ceremony, and cultural life. Talking circles remain an important part of many Native American tribes today.

Lorelei understood the importance of the talking circles and envisioned a diabetes public health message that reflected the core values of Native spiritual beliefs and stories, artwork, and appropriate language to meet our current times. Sharing a traditional prayer, sharing a Native American meal, sharing scientific knowledge, and using storytelling were all elements integrated into the diabetes talking circles model. By using this approach the diabetes talking circles strengthened traditional ties while reinforcing positive food habits and exercise. It provided physical, emotional, and spiritual guidance and support to many Native Americans afflicted by the epidemic.

The Evidence  We can overcome this epidemic and restore our health.

Diabetes Talking Circles moves from a vision to being recognized as a “Best Practice” by the Indian Health Service.

In order to carry out this model in Native American communities, diabetes talking circles had to be tested scientifically to demonstrate their effectiveness. In 1998, the Center for American Indian Research and Education (CAIRE) received a four-year grant from the National Institute of Nursing Research (NINR) to design, develop, evaluate, and test talking circles as part of a community diabetes program. The research team, headed by Felicia Schanche Hodge, Dr. P.H., worked in collaboration with Lorelei, the Seva Foundation, and CAIRE to carefully study the impact of diabetes talking circles.

The four-year research and education intervention was conducted among Native American adults living with diabetes or at-risk for diabetes across four Northern Plains reservations: the Winnebago Reservation in Nebraska; and the Yankton Sioux, Rosebud Sioux, and Pine Ridge reservations in South Dakota. Native American staff at Indian Health Service (IHS) locations and a team of researchers began by having focus groups to investigate culturally based practices and strengths.

“Wellness warriors don’t deny diabetes. They fight it!” Participant in Project Focus Groups.

The purpose was to increase knowledge of diabetes and how it is treated, and to provide nutritional and physical exercise as part of diabetes prevention and treatment.
The data generated included pre-test and post-test surveys, associated anthropometric measures (such as weight and body fat), medical chart reviews, and dietary recalls.

The research results demonstrated statistically significant changes that were observed in several areas:

- Fatalistic attitudes toward diabetes were significantly reduced
- Diabetes knowledge was improved in several areas.
- Knowledge improved significantly regarding dietary fat.
- Dietary fat and fiber knowledge increased among the male intervention group members.
- Exercise knowledge increased significantly.
- Diabetes treatment compliance improved.
- Exercise increased in frequency.
- Obesity levels (BMI) were reduced.

“We must create a healthy community where this disease cannot survive.”

The study demonstrated the strength and success of culturally-appropriate diabetes intervention for Native Americans. The talking circles model became known as the Diabetes Talking Circles (DTC). It changed fatalistic beliefs and presented an educational program that was readily adopted as an empowerment step toward the prevention and control of diabetes among Native Americans living with or at-risk for diabetes.

Today the DTC Curriculum¹ is used by IHS across the nation and is adopted as a Best Practice model within the IHS Special Diabetes Program, under the Community Advocacy section.

¹ These materials were produced with support from the National Institutes of Nursing Research grant #RO1NR04722, Felicia Schanche Hodge, Dr.PH, Principal Investigator, Center for American Indian Research and Education (CAIRE), University of California, Lorelei DeCora RN BSN, Field Project Director, Seva Foundation - Native American Diabetes Project; Betty Geishirt-Cantrell, MSSW, MBA, Project Director, CAIRE, University of California; and Arnell Hinkle, RD, MPH, Collaborating Investigator, and CANFit.

The Work  Lorelei is an advocate for her people.

Starting in 1997, Seva recognized that in order for the DTC model to be successful in Native American communities, a permanent position was needed to conduct training and awareness. In September of 1997, Lorelei became the Director of the Diabetes Wellness Program at Seva.

“Oftentimes in my position with the project and through connections in vital areas of the public health arena, thanks to Seva, I’m able to be an advocate for our Northern Plains tribes.”

In 1997, with permission from the Winnebago Tribal Council, Seva rented an office for Lorelei. It was there that partnerships grew to
promote community-based programs reflecting preservation and an opportunity to build a strong community network that supported the Diabetes Wellness Program. Lorelei’s dedication to the program was demonstrated by her ability to bring people together and bring her visions to life.

She is not only an activist, an advocate, a grant writer, a director, a nurse; she is a Native American entrepreneur.

In 2004, Seva and Lorelei partnered with the Centers for Disease Control and Prevention, Native Diabetes Wellness Program (NDWP), to increase dissemination of the DTC model to health care providers.

Lorelei has conducted DTC facilitator trainings for tribal health providers so that they can return to their communities with the DTC model. In total, as of April 2009, she has trained in all 12 IHS areas representing 149 Tribal Sites with 844 Health Care Providers serving Native American/Alaskan Native People in diabetes prevention and treatment in the US and Canada.

Today, she continues to train and educate IHS health practitioners. The model emphasizes preservation of traditional foods and community gardens and has inspired other tribal health representatives to form exercise and similar health groups for adults and children.

“As our ancestors looked out for us, we need to look out for our children and grandchildren. I want our people to have good lives. Together, let’s build a diabetes-free future for our children.”

**Preservation**  *Bringing back traditional foods and wellness to the community.*

In 1997, as part of Lorelei’s role as the Director of the Diabetes Wellness Program, she worked on community projects that were focused on returning to traditional foods and fostering community exercise and wellness.
Lorelei worked with the Wellness Coalition and the Winnebago Tribe’s Whirling Thunder Wellness Program to pull community resources for these projects.

“When the people put their minds together on behalf of the good of the people, nothing is impossible!”

In promoting a return to traditional foods, she worked closely with the Winnebago Tribal Buffalo Herd, a partner of the Wellness Coalition.

Two bison were given a naming ceremony; one was named “Wavy Gravy” after one of Seva’s founders and the other was named “Seva.”

“The buffalo were grazing close to the fence where I was, so I watched them for awhile. The bull came right up close and checked me out, so I talked to him. Told him who I was and what I’m trying to do with the Project. He relaxed and began grazing. It was a real spiritual experience for me. At the same time as I was talking to him, an eagle circled over us. I left feeling I’m on the right track with what I’m doing.”

The Wellness Coalition and the Whirling Thunder Wellness Program partners held “Healthy Choices” food stands at Annual Powwows and “Traditional Food Booths” at Tribal Health Fairs. They also established a Wellness Center and numerous Community Gardens.

“We harvested corn from our garden sites and dried it in the traditional way.”

“The buffalo, deer, corn, squash, beans, wild turnips and berries, and other traditional foods provided nourishment needed by the bodies of Indian people. These foods were our allies. When we invite them back to our table, we will have taken the most significant step in eliminating the enemy, diabetes.”

The Partnerships “Doing work in a good way”

From the very beginning Seva believed in the work and visions of Lorelei DeCora to improve the health of Native People. The unique partnership began in 1982, when Seva awarded the initial funding to Lorelei to establish the Porcupine Clinic that became the first health clinic in the country to be owned and operated by a Native American community. In addition, Seva supported and partnered with Lorelei in 1997 to begin implementing the diabetes health model in Native American communities and awarded small grants for gardening and wellness projects.
Since 1997, Lorelei has served as the Director of the Diabetes Wellness Program at the Seva Foundation from the Winnebago location. The Seva Winnebago site represented the importance of having a physical presence within Native American communities.

Another significant partnership is the involvement of the Centers for Disease Control and Prevention (CDC). In 1997, Lorelei initiated a dialogue with CDC that later led to her involvement as a member of the National Diabetes Education Program’s (NDEP) American Indian/Alaska Native Work Group. NDEP is a joint initiative of the CDC and National Institutes of Health. For more information, please visit: http://www.ndep.nih.gov.

In 2004, Seva and Lorelei partnered with the Centers for Disease Control and Prevention, Native Diabetes Wellness Program (NDWP), to increase dissemination of the DTC model to health care providers through facilitator trainings in reservation and urban Native American communities across the US and in Canada.

“We knew Lorelei and we knew her strength. She is the real spirit of this.”
T. Stephen Jones, retired CDC public health service officer.

In 2007, the NDWP, contracted with artist Sam English to create the Traditions of Gratitude Series, a three image poster set. One of the images, Around the Fire: Talking Circles for Diabetes Care and Prevention, honors the tradition of talking circles and the partnership of Lorelei, Seva, and the CDC in supporting diabetes talking circles in Native American communities.

Starting in 2008, Lorelei and the NDWP have partnered to develop primary prevention talking circles for children. These talking circles for Native American children are a natural outgrowth of the DTC model, and are based on the Eagle Books series. http://www.cdc.gov/Features/EagleBooksExhibit

Developed by the NDWP in collaboration with the Tribal Leaders Diabetes Committee and the Indian Health Service Division of Diabetes Treatment and Prevention, the Eagle Books provide health educational messages that focus on promoting health and preventing type 2 diabetes.
The stories are by Georgia Perez, a Community Health Representative for Nambe Pueblo for 19 years. They are vividly illustrated by Patrick Rolo of the Bad River Band, Ojibwe, Wisconsin, and Lisa A. Fifield Oneida Tribe of Wisconsin, Black River Clan.

In reading, “Through the Eyes of the Eagle,” “Knees Lifted High,” “Plate Full of Color,” and “Tricky Treats,” children learn about a young boy and his friends engaged by a wise eagle, a grateful rabbit, and a clever coyote in learning about traditional ways of health, wise choices about food, and the joy of physical activity. For additional information on the Eagle Books: [http://www.cdc.gov/diabetes/pubs/eagle.htm](http://www.cdc.gov/diabetes/pubs/eagle.htm)

---

### Milestones

**1980**
Seva first approached the Black Hills Survival Gathering to ask “How can Seva be of service?” The co-founder of the Black Hills Alliance and the Women of All Red Nations (WARN) responded. Her name was Lorelei DeCora.

**1982**
Seva awarded initial funding to Lorelei (Seva Board of Directors from 1982-1996) to establish the Porcupine Clinic and later held benefit concerts called “Cowboys for Indians” to raise funds to build the facility.

**1992 - 1996**
Lorelei researched the diabetes epidemic by understanding what approaches were in place, talking within the community and with relatives and elders. She envisioned a health model that would draw upon traditional values.

**1997**
Lorelei accepted the position as the Diabetes Wellness Program Director at Seva. She wrote the article, “The Legacy of Displacement” that described the Native American epidemic of type 2 diabetes and the importance of reintegrating traditional foods and diabetes prevention.

**1998 - 2002**
DTC research was funded by the NINR through a partnership with CAIRE and Seva’s Diabetes Wellness Program.

**2001**
Publication of “A Traditional Food Book, Recipes from the REZ,” produced by Lakota Express, supported by a NINR grant; a joint project of CAIRE, and Seva’s Diabetes Wellness Program.

**2002-2005**
Lorelei was a Winnebago Tribal Council Member and Tribal Leader Diabetes Committee Member representing the Aberdeen Area.

**2002 – Present**
Training of the DTC Curriculum to health care providers across all 12 Indian Health Services Areas.

**2004**
NDWP partners with Seva and Lorelei to increase dissemination of the DTC model to health care providers.

**2006**
DTC program recognized as a “Best Practice” by IHS.

**2008**
Lorelei and NDWP partnered to develop primary prevention talking circles for children.

**2009**
Lorelei will be a presenter/speaker on the DTC model at the 9th Annual IHS “Advances in Indian Health” Conference in April.
The Support

The Diabetes Wellness Program and Diabetes Talking Circles are successful due to the dedication and efforts of many that continue to share the same vision of fighting this disease and lessening the burden of human suffering.

We would like to give acknowledgement to the following partners and friends of this program:

Lorelei DeCora
Felicia Schanche Hodge
Betty Geishirt-Cantrell
Arnell Hinkle
Thomas Welty
Roxanne Struthers
Doug Lehmann
T. Stephen Jones
Dawn L. Satterfield
Lemyra DeBruyn
Center for American Indian Research & Education
National Institute of Nursing Research
Centers for Disease Control and Prevention- Native Diabetes Wellness Program
Area IHS Diabetes Consultants and Diabetes Coordinators
Tribal Diabetes Directors
Native American Program Advisory Group
1st Nations Development Institute- Native Food Systems Initiative
Robert Wood Johnson Community Health Leadership Program
Winnebago Tribe of Nebraska
Winnebago Wellness Coalition
Ho Chunk, Inc.
Oglala Sioux Tribe
Yankton Sioux Tribe
Rosebud Sioux Tribe

This article is submitted to honor and celebrate the Diabetes Talking Circles and is completed by the Seva Foundation, Native American Program, with the guidance of Bonney Hartley and Lorelei DeCora. With special thanks to Lorelei DeCora for sharing her personal reflections and professional experiences and to T. Stephen Jones for his insight and perspective. – Andrea O’Hare, March 2009

Publications

To download the DTC training materials free of charge, please visit: [http://www.seva.org/dtc](http://www.seva.org/dtc)

For a list of sites that have been trained in this model, please [click here](http://www.seva.org/dtc).

For additional information on Diabetes, please visit these internet sites:

Indian Health Service Division of Diabetes Treatment and Prevention: Provides current diabetes news, program and training information, and resources.
http://www.diabetes.ihs.gov

CDC Division of Diabetes Translation: Information for the public and professionals about diabetes, including research, statistics, and educational publications.
http://www.cdc.gov/diabetes/

Children’s Eagle Books are a series of four children’s books that provide a health educational message that focuses on diabetes prevention.
http://www.cdc.gov/diabetes/pubs/eagle.htm

Sources Consulted:


Seva Foundation internal program documents: Native American Diabetes Project, Lorelei DeCora Narrative Summaries (1996 – 1999); Seva-Spirit of Service Newsletter (Spring 2006).

Images: Photos provided by Seva Foundation, CDC, NDWP, T. Stephen Jones, Mary Pember, and Veronica Davison.


Quotes: All of the quotes included in this document are from Lorelei DeCora, unless otherwise noted.