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Project Title: "Breaking our Barriers: Reservation-Wide
Collaboration for Comprehensive Public Access to
Specialized Health Care and Wellness Information
Via Telecommunication"

Prepared for:

**Leech Lake Health Division
118 2nd Street NW
Cass Lake, Minnesota 56633**

Prepared by:

Carol Brieschke, Consultant
9057 Blaisdell Avenue S.
Bloomington, MN. 55420

952-888-5625
cbrieschke@aol.com

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Final Project Report

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Contact: Joel Stokka, Project Coordinator
Address: Leech Lake Health Division
118 2nd Street NW
Cass Lake, MN 56633
Phone: (218) 335-4500
e-mail: jstokka@mail.com

Project Description

The primary goal of the project was to “create a sustainable tele-wellness infrastructure starting with building capacity in the area of health and reaching into the community and schools,” to be accomplished by the installation of telemedicine equipment with videoconferencing capability to create electronic linkages between the Leech Lake Health Division (LLHD) and Indian Health Service at Cass Lake, Minnesota and five remote satellite clinics serving nearly 12,000 active patients who are residents of the Leech Lake Indian Reservation. The original project described in the grant proposed a focus on diabetic health care; increased access to primary and specialized health care; and the reduction of patient and staff cost and inconvenience of travel in order to receive medical care.

Technology proposed for implementation of this project to be used in this remote area of Northern Minnesota included: live links, peripherals, and specialized cameras would be instrumental in closing the gap in resident’s access to specialized medical care. An in-home technical approach using a telephone homebound video system was identified and selected to monitor homebound diabetic patients.

Expected Outcomes

The advent of technology would enable the remote area satellite clinics to have real-time access to the medical providers who rotate among all five clinics during the week. Video conferencing would be used for consults with specialists in distant cities, and Internet access would allow staff increased communication and access to medical research and resources. Diabetic retinopathy screening would become available on the Leech Lake Reservation which was expected to increase diagnosis and treatment of eye disease common to diabetics. Additionally, training and free use of computers with internet access would be available in the satellite clinics the community and schools.

Original Partners and New Partnerships

The original plan called for a close partnership and working relationship with Regions Hospital located in Minneapolis, approximately 250 miles away. Regions Hospital has significant experience with the technology proposed, and could have provided the training and technical assistance necessary to implement a technology-based medical program at the Leech Lake Reservation. Unfortunately, the partnership agreement with Regions Hospital was never actually committed. The issue was complicated by the time frame in submitting the original grant application which was not funded, and the resubmission a year later. It appears the grant was resubmitted the second time without a signed updated agreement with Regions Hospital to be the partner organization. Regions submitted a letter of support, but not a letter of commitment to the partnership as in the previous years' grant application. When the Project Director left two months before the end of the original three year project, the installation of technology had just reached the point where the partnership activities was to begin. The new Project Director was able to find a new partner and ultimately meet the major objective of the grant which was to install the necessary technology and provide access to medical services via real time video-conferencing in remote areas.

New Partnerships Developed

A new relationship was developed with Merit Care Hospital in Fargo, North Dakota located approximately 150 miles west of Leech Lake, has the largest telemedicine program in Minnesota and North Dakota and services a large percentage of small town clinics throughout the region. The Leech Lake Telemedicine Coordinator received technical assistance and training in technology for configuration and networking and uses of equipment for this project which was instrumental in selecting, installing and determining the best placement of the equipment. Leech Lake Health Division held a series of meetings over the term of the project with Merit Care toward the end of the second project year to develop collaborative working relationships with specialists in the Merit Care Hospital system specifically addressing the need for a consulting dermatologist and ENT Specialists who could see patients via real time video conferencing. This process has taken nearly a year, during which time LLHD has been actively developing additional working relationships to meet the needs of patients at LLHD Satellite Clinics.

Additional Partners

A new partnership forged with Sister Kenny Hospitals in Minneapolis at the end of the extension year provides two hours a day for real time teleconferencing for consults with Orthopedists and Physical Therapists. Using teleconferencing, patients can come into the Satellite Clinic and with the assistance of a clinic provider receive consults and directions for further therapy. The cost in time, travel expense, and physical discomfort of the patient has been reduced according to patient satisfaction surveys, and they are more likely to keep their appointment when they only have to go to the local clinic rather than spend the day driving to a larger city. At the time of this report the hours of access with Sister Kenny are limited, so efforts are underway to forge relationships with other providers as the demand for various specialists is determined.

Cultural sensitivity training was provided to the new collaborating partner in the form of one day of training to staff of Sister Kenny Hospital. Two instructors from Leech Lake Tribal College provided the training via telecom to two administrators and three practitioners. The transmission was videotaped and reused for additional staff.

Project Outcomes

The grant proposal was vague and non specific with the primary objective of creating an *infrastructure for technology that would increase access to medical care in remote areas*, with a secondary goal to ensure compatible technology for educators and community members to access medical information via the internet and on the tribal website.

The primary outcome of accessing technology to reduce disparity in health care services in remote areas has been achieved, although not in the way it was originally planned, or to the extent expected by the end of the project period. The secondary outcome to ensure compatible technology throughout the reservation has not been achieved due to irreconcilable differences in technology between the satellite hook ups used the education system in the state, and all other divisions on the reservation and the Tribal Government.

The anticipated outcome of improved telecommunication between clinics through the use of teleconferencing and e-mail is being implemented, but still in the process of training staff to use the new technology. However, despite the need for additional and ongoing staff training, significant progress has been made in accessing specialty medicine for the benefit of patients in remote areas.

Diabetic Retinopathy testing was one of the major outcomes of the project, resulting in one machine purchased and two people trained to conduct the tests. Patients no longer have to travel to other cities to get this testing done. Twenty patients were tested in a field study to determine the best way to use the equipment. It was found the sensitive and rather large equipment was not easily transported from one clinic to another, so the project was delayed until a new partnership with Joslin Vision Network was developed. This partnership is discussed on page 8 of this report.

Project Outcomes for the use of Home based telemedicine equipment linked with the public health nurses estimated 60% of the population would maintain communication with medical providers in this manner for blood pressure, blood glucose testing, and heart rate monitoring. A

pilot test conducted using this technology proved to be a challenge with the Leech Lake population for a number of reasons discussed later. Projected outcomes related to the use of technology in patient homecare have not yet been realized, but an alternative solution currently being tested uses video phones that operate on regular phone lines.

Linkages with Education and Community

Installation of the video conferencing in the schools proved impossible if they were to remain networked with the statewide public school system. The original plan to video conference link with classrooms for health education was not implemented because extensive upgrades would have been necessary due to incompatible equipment and technology. All public schools use ITV satellite transmission and the Health Division administrative offices use DSL. Furthermore, no money was budgeted for upgrades, or even for training at the schools. Training on use of technology for health research and prevention purposes was not done in this project because the nutritionist didn't have time or money in her budget to provide training at the schools. An interim solution was to open a health clinic at the Bug-O-Nay-Ge-Shig School Tribal School where a separate funding stream provides access to health education.

Obstacles Encountered

The major barriers to implementation of technology project stem from a lack of concrete project development and planning prior to application, and lack of knowledge about the community to be served. Leech Lake is a Native American Indian Reservation populated with many elderly people who have lived their whole lives fifty miles from the nearest store, and without telephones or even electricity in some cases. Many factors were apparently not considered in the development of the grant application, nor was there any evidence of pre-planning in regard to the current state of technology versus the planned technological program to be implemented. A third factor causing problems for those hired to carry out the project was the absence of well defined objectives and expected outcomes in the project design. Further complications were due to a failed partnership; no consultant brought into the project to design the evaluation criteria; and Tribal Administrative situations that resulted in a high degree of staff turnover. What was to be a

three year project had to be extended to four years, but through perseverance and the ability to adapt to changes in technology and circumstances, is now showing positive results.

Implementation Process

The project was implemented over a period of four years as many unforeseen challenges and barriers surfaced during the actual physical installation of technology and service lines including: *delays with area tele-communication service providers in reaching agreements on contracts and services; construction delays on the new medical facility in Cass Lake where the equipment was to be installed; and tribal politics and changes in tribal administrative policies resulted in wide scale staffing changes that seriously affected medical staff levels that had to be resolved before the project could move forward again. The result of the wide ranging delays was equipment purchased and waiting for the lines to be installed so it could be hooked up, other equipment unavailable or obsolete within three years, all of which resulted in additional time needed to research alternative solutions which in turn forced the project to apply for a one year extension.*

Technology

Plans to utilize T1 land lines for internet and broadband access created an immediate problem because telephone service in remote areas was non-existent or incompatible with service being used in other areas of the reservation. It was well into the first year of negotiations with the local telephone company before an agreement was reached about installing high speed data lines to remote clinic areas. Meanwhile, analysis of existing technology providers on the reservation, and usage at various divisions in Tribal administration took the better part of a year and revealed a patchwork of four different telecommunication access carriers serving the reservation. By the time the various carriers were sorted out near the end of the second year, changes in the tribal administration delayed signing of the contracts necessary to begin the work. During this time it was learned that DSL would soon become available to this area. Due to repeated delays with the local telephone companies for access of a trunk T1 line to the satellite clinics, it was easier to wait six months for DSL to become available in this area than to install high speed data lines.

What seemed to be an unfortunate setback proved advantageous to the Tribe because the original plan was based on poor cost projections for using T1 lines at the remote clinics. The T1 lines would have cost \$2,300 per month to maintain, adding nearly \$27,600 to the annual LLHD budget. The DSL cost is minimal at \$100 per month at each site, for a total expense of \$3,600, saving LLHD \$24,000 a year.

Staffing

The LLHD Technology Project was run by the Project Coordinator for the first 18 months of the project as the position for technology coordinator was advertised, but remained unfilled due to lack of qualified applicants in this rural area. A consultant was hired into the Technology Coordinator position for a period of seven months until he was reassigned to another project, once again leaving the Project Coordinator managing the project alone. Three months short of the end of project year three, political influences at the tribal administrative level affected the Health Division resulting in the loss of all senior management, including the Project Coordinator, and 50% of the home health aids. The Technology Coordinator was reassigned to additional projects for a period of three months, slowing project progress. Two months before the end of the three year project, the Technology Consultant was hired into the Project Coordinator position and immediately applied for and received a 12 month extension in order to complete implementation of project goals. This resulted in another delay, as it was necessary to rebuild the staff/health division before work could continue on the technology project.

Analysis of Data

Analysis and data collection for this project was to be determined by an outside evaluator who was to develop the cost analysis criteria; determine the data collection criteria, and how data was to be collected to complete the study proposed in the grant evaluation plan. This work was to have provided the basis for all results and findings associated with the objectives of the project concerning patient interaction. The consultant was scheduled to be brought in early in the process was never hired due to the long delays in getting basic T1 telephone lines installed for the proposed technology. Without an evaluation consultant to assist in setting up the data collection process, no data other than patient satisfaction surveys and teleconferencing consults

that took place in the extension year was collected. Quarterly reports made to the Director of Health, but no record of meetings, monthly teleconference planning notes, or documentation for the provision of training with the original partners was available for review. It is possible files were lost during the staff transitions that took place over the four years of the project, but after the original Project Director left, LLHD was unable to recover any computer data or records regarding the progress and work done on the project to date. Some paper files including some quarterly reports, correspondence, supporting documentation for equipment, and the previous years grant application and internal accounting reports were found. The lack documentation and the need to rehire staff meant many steps had to be retraced before moving forward.

Digital Retinopathy Screening

The grant specified purchase of one digital retinopathy camera to use at two locations which would ensure retinal screening of diabetic patients for the diagnosis and prevention of eye disease. The camera was purchased in the last year of the project and placed at the Cass Lake Health Division administrative building after resolving construction delays. The proposed process would have required sending the images to a diagnostic evaluator to be read. An investigation showed this method to be cost prohibitive to the Leech Lake Health Division as four years ago Medicare did not pay for store and forward application; only live consults. LLHD would have had to budget for the potential evaluation of 400-600 images each year at a cost of \$25 per reading, a potential cost of \$15,000 not budgeted in the planning process. The end of project year three found LLHD still trying to determine which vendor to use for retinopathy services.

As part of LLHD efforts to ensure sustainability of the project other collaborations were sought. In the fourth year of the project, LLHD had the opportunity become part of the Indian Health Services network throughout the United States in collaboration with Joslin Vision Network (JVN) at Harvard Medical School. Leech Lake was the 16th tribe in the USA to receive the grant which pays for the reading and diagnosis of the films for the next five years. The grant is renewable thereafter and will be billed to Indian Health Services or Medicare for ongoing service. JVN trained two tribal employees as digital retinal imagers to conduct the eye exams.

The computerized system automatically transmits the films to Indian Health Services (IHS) in Phoenix, AZ to be ready and diagnosed by certified readers. The JVN process eliminates the cost of reading the images, cuts handling time and diagnosis time, and the data is automatically entered into the IHS databank where it is being used to build a national database for Native American Health. This service was implemented during the last extension period of the grant, and it is now possible to include a retinal examination as part of the diabetic care of 1200 patients at the Leech Lake where there are 800 active cases diagnosed with diabetes.

Home Based Telemedicine

In the first year of the project LLHD purchased and installed two POTS units and conducted a pilot test in two homes, one with an elderly couple and one with a stroke victim. It was immediately apparent this type of technology was not suitable for this population in this remote area and under these circumstances. The elderly population is not technology driven, and the original estimation of 60% of the population having telephones did not consider the fact that nearly half are using cell phones because they are much less expensive to use than a regular land line. In this remote area where nearly every call is considered long distance, a 30 minute consult would cost the patient at least \$6, adding \$48 a month to their expenses.

The video equipment did not work as planned early in the project because it was not possible to use real time video transfers unless the patients had high speed internet access. Another consideration was that the original project budgeted only \$12,000 for 12 in home units, when the actual cost per unit was over \$3,000 which would have allowed only four units. By implementation time the manufacturer had gone out of business and technology had improved significantly on video phone systems, so the decision was made was to step down the technology and purchase and use to use a different video phone system. The alternate video phone system uses manual peripherals which makes it easier for diabetes patients to use a digital scale for weight check; a battery operated blood pressure cuff, and glucose monitoring while on video phone connection with the satellite clinic.

Specialty Consults via Teleconference

In November 2002 an in-home pilot test was started with Sister Kenny in-home tele-rehab services. Seven to nine people participated in a clinical study over a six month period to test the application to patients in LLHD remote clinics. Since that time real time tele-rehab is being used in two remote clinics (Inger and Ball Club), the Health Division offices and the Cass Lake Indian Hospital. Specialty providers were sought to address the demand for rehabilitation and physical therapy services from Merit Care Hospital (Fargo) and Sister Kenney Hospital (Minneapolis).

Clinic providers were trained through video conferencing in therapy assistance. Clinic nurses received ½ day of training, and home visiting nurses received ½ day. The result is that home visiting nurses are now able to provide assistance to the orthopedic therapist via video cam conference by assisting the patient to demonstrate range of motion, pressure testing, and other maneuvers required by the orthopedic specialist.

The primary medical facility in Cass Lake and two of the most remote clinics were selected to receive video conferencing technology. Both satellite clinics are approximately fifty miles from the area hospital or clinic, and have significant numbers of patients in need of specialty care, and share a number of characteristics reflective of the population being served. For example, both clinics have resorted to walk-in services only because people don't keep appointments; they know when the clinic is open and they show up and wait to be seen. Both of the remote satellite clinics are staffed by one nurse one office administrator. Two Physician's Assistants and one nurse practitioner rotate between the LLHD clinics and average 100 patients a month in the winter and more in the summer months. The anticipated Internet use at both clinics by community members has been increasing slowly due to the low level of computer literacy among the adult population and the low interest of elders for new technology. The elderly are more likely to ask the clinic staff to look up information on medications and print it out for them. The internet is used daily by one or two of the younger community people.

Inger Clinic. A pilot study was completed with a limited number of patients only to determine the effectiveness of tele rehab and client response to it. Specialty areas have now been

identified and LLHD is ready to expand the program by recruiting new providers to meet emerging needs. Inger Clinic tele-rehab clinics are held every other Monday, and between January and June, 2003 there were 22 visits involving 5 patients with musculoskeletal issues. One female had 3 tele-consults, and four male patients between the ages of 46-74 used tele-consult 19 times. All patients reported they would have had to travel one hour for services if this option was not available. In six of the 22 visits the patient would have been accompanied by a family member or other. When reported (many surveys incomplete) all patients rated audio and video good or excellent when applicable (15 of 22 visits). All patients reported they would choose a tele-visit over an in-person visit, giving reasons of time, expense of travel and fatigue. 19 of 22 patients reported their satisfaction level as (8) excellent or good (11). Only seven to nine patients are currently using the teleconferencing option due to the limited availability of services under the grant held by Sister Kenny which provides consults two hours every other week. The initial consult with an Orthopedist takes just under an hour and the follow up sessions take 30 minutes at which time the physician evaluates the progress.

Additional problems identified and resolved with implementation of the tele-therapy program are associated with characteristics of the population using bi-monthly services. It was discovered that during the two weeks at home they didn't do the exercises regularly, correctly, or failed to exercise at all. The patients had no support mechanism in place between consults, and were unable to maintain the equipment at home. The low income levels of the patients proved to be a major barrier to maintenance of home therapy as they did not have access to, nor could they afford to purchase the necessary equipment. The solution was to hire a Registered Therapist Assistant who makes home visits to each patient twice a week to keep them on track with their therapy. Patients now come to the clinic on the off-week to make sure they are doing the exercises correctly, and the clinic now furnishes all the equipment needed at home such as stretch bands, weights, and other therapeutic exercise equipment.

Ball Club Clinic. This clinic experienced several unique problems which impacted the progress of implementing teleconferencing capabilities and rehabilitation therapy services, causing delay well into the fourth year of the project. In addition to the delays in getting telephone lines with

high speed internet capability and waiting for the opportunity to switch to DSL services, the clinic was the target of vandalism twice: once in 2000 just after the video conferencing equipment had been installed, and again in 2002 when the computers were damaged and the video conferencing equipment was stolen. The clinic was shut down for four months to make repairs and to make replacement of the damaged computers. The vandals were apprehended and the video conferencing unit was returned undamaged after five months and reinstalled under new security measures. Clinic staff has received training on use of teleconferencing and has limited experience thus far, but is starting to use the equipment for tele-rehab consults for physical therapy. An unanticipated need for more training of the clinic staff on use of the equipment has delayed the implementation of tele-rehab consults at this clinic, and has only started to be used for teleconferencing. It is expected once staff becomes familiar with the equipment and realizes the potential uses for interfacing with the main medical facility, it will become second nature to use it not only for communication with rotating physicians, but also for specialty consults. This equipment was installed and began functioning in the extension year of the project.

Project Design Change

After needs were determined for diabetic retinopathy screenings, and the home video phone contact with diabetic patients, additional needs of diabetic patients were identified, such as ongoing physical therapy, dermatology, and other specialty medicine. Rather than force the original project design when it was apparent this population has significant needs in related areas, the decision was made to make the best use of the technology by creating new linkages with larger health institutions and clinics in the surrounding area and address the immediate and most pressing needs of this population. This decision resulted in initiating relationships with two hospitals/clinics for children's behavioral health, orthopedic diagnosis and ongoing treatment, and other specialty medical services as needed to meet the demand. Changes in the availability of technology over the four years of the project; changes in health care reimbursement; and changes in telemedicine as an emerging industry required LLHD to be in a state of constant awareness and reaction to gain advantages in developing state of the art medical solutions.

Project Accomplishments

Leech Lake is the only tribe in MN utilizing telemedicine to any extent in Native Health Communities, and it addresses the need for access to medical care in this geographic area where the alternative is to drive 30 to 50 miles one way to the nearest specialty clinic. Video conferencing links installed at Cass Lake Indian Hospital and LLHD administration is used is used by the medical staff when they need to consult with an on-call physician at the hospital, or at a remote site. The units are also available for use in communicating with the satellite clinics, for teleconferencing staff meetings; and for access to trainings to reduce the costs of travel and lost time for patient care.

Overall accomplishments include a working telemedicine/ telecommunication infrastructure throughout the reservation that uses state of the art technology at a sustainable cost to the Health Division. A working and functioning retinopathy program has been created and is sustainable well into future years through partnerships and grants from Indian Health Services is expected to serve a minimum of 800 patients a year, whereas previously only 30% (240) of the active cases received annual eye exams for diabetic retinopathy.

Access to health care in remote clinics through the use of telecommunication has begun to reduce the disparity of access to health care. Video conferencing is being used for clinical visits with Sister Kenny Hospital from the Inger Clinic where patient satisfaction reported for increased range of motion is attributed to regular tele-rehab consults and home visiting nurses. Home care using video phones has been tested and clear parameters have been determined for using it with this population. Communities that previously had no access to the Internet now have free use of computers with Internet access at two remote clinics, and the Tribal website is available to provide linkages to health care information on the web.

Future

Staff predicts patients use of video teleconferencing will soon increase as they become used to access to technology, and as additional relationships are developed with medical specialists in addition to the physical therapists and occupational therapists now being utilized through Sister Kenny Hospital. Staff predicts 90% of the physical therapy patients with access to satellite clinic

teleconferencing will use it regularly once the collaborating hospitals are in place. These estimates are informally based on high numbers of patients with chronic pain and accidents who are currently referred to distant cities for treatment.

Future Project Expansion

LLHD has become aware of the large potential for teleconferencing consults in behavioral medicine, especially for children and teens who readily accept the technology. Expanded use for tele-psychiatry is under consideration at the Inger Clinic. As the clinic staff becomes familiar with the use of technology and video conferencing equipment, LLHD will contract with a child psychiatrist from a larger clinic in Brainard, MN to consult with younger children via video conferencing. LLHD is also exploring the option to expand telemedicine orthopedic rehab services by accessing Medicare in order to serve a larger population because at the present time a patient has to wait six months to get an appointment for physical therapy at the Indian Hospital. LLHD has recently developed a working relationship with the Shriners' Hospital in Minneapolis for orthopedic tele conferencing for physical therapy which will expand the PT services available at Leech Lake.

Sustainability over Time

The series of delays experienced during the implementation process were beneficial to the long term sustainability of the project. First, the delay resulted in getting better technology at a lower cost. The use of DSL instead of bringing in trunk lines saved money on the installation and equipment, and will continue at a reasonable cost in future years. Technology now being used for specialty medical consults is cost-effective and billable to Medicare. Digital Retinopathy exams will be sustained through Indian Health Services in the foreseeable future. Home telemedicine costs for home phones and equipment will be picked up by LLHD and will be sustainable through cost savings associated with less travel by home visiting nurses. Internet connections for community use will continue to be maintained at the remote clinics for staff and community use.

Patient Satisfaction: Patients have increased access to health care at a faster, lower cost, and technology has increased access to specialty medicine services, and broadened the range of services a patient can receive. Continuity of care is now more available because patients are more likely to utilize medical specialists when they don't have to travel to other cities for treatment. Native American Elders especially show a preference for video use over travel because of cost savings for them, and because it eliminates a day long excursion of 60 to 90 miles round trip that incurs out of pocket expense of travel and meals. Many patients are not able to drive which places an additional burden on family members who spend the whole day providing for, or assisting with the travel to access medical services off the reservation.

Lessons Learned

Partnerships: The need for careful and comprehensive planning to include current dated and signed memorandum of agreement with participating organizations that specifically spell out the terms, contributions and costs for each phase and year of the project.

Need for comprehensive planning and cost estimation: The project needed a full year of planning prior to implementation. The ideal situation would have been to have a person on staff knowledgeable in project planning, and conversant with technology and medical application to avoid the mistakes made in assumptions regarding the existing state of technology on the reservation. Similarly, cost estimations applied in estimating the project budget overlooked the most basic costs associated with implementation of the project. Timeliness of the project was completely dependent upon outside influences that could have not been controlled, but an increased awareness of alternatives could have moved other aspects of the project along at a better pace. For example: pre planning done in the form of community surveys, and baseline data and statistics compiled would have provided an important set of factors from which to measure achievement and progress over the course of the project. Reliance on an outside consultant for essential data analysis would have been better achieved as an ongoing function of project staff, not dictated by the time constraints associated with a hired consultant.

End.