

GREAT LAKES INTER-TRIBAL COUNCIL, INC.

Honoring Our Children Project

CFDA #93.926E

I. Overview of Racial and Ethnic Disparity Focused on By Product

When the GLITC Honoring Our Children Project (HOC) addressed perinatal health disparities in 2001, twenty-three Wisconsin Department of Health and Family Services, Division of Public Health, and Bureau of Family and Community Health staff had conducted the Family Health 2000 Needs and Strengths Assessment to learn what perceived health issues were affecting families and what needs were being addressed at the local health agencies. Great Lakes Inter-Tribal Council, Inc. (GLITC) has a long history of representing the eleven tribes of Wisconsin and upper Michigan. GLITC was able to address the tribes' many issues of health and bring much needed services to the tribes by writing and winning federal, state and private foundation grants. In addition, GLITC works closely with WTHDA (Wisconsin Tribal Health Directors Association) and is very much aware of the health issues related to the families living in the service areas of the tribal reservations.

Using the state's needs assessment data, and what GLITC knew already about the tribal health systems and communities, the project selected to focus on the following three needs: 1) early access to prenatal care with associated risk factors of maternal alcohol, tobacco, and other drug abuse/use; (2) transportation; and (3) provision of a culturally competent health care service delivery system.

The three-year average (1996-1998) of Native American women who smoked at that time during pregnancy was 46%. This data, we believe, was under-represented. Data suggests in studies that smoking during pregnancy is related to Sudden Infant Death Syndrome (SIDS). The Wisconsin American Indian Infant Mortality Review Project (WAIIMR) found that during the period of 1983-1987, 27.2% of Native American infants died from SIDS compared to only 19.5% for all races in Wisconsin. Smoking during pregnancy is also linked to preterm delivery and respiratory problems in babies. The use of alcohol, tobacco and drugs during pregnancy is a major risk factor for low birth weight (LBW), very low birth weight (VLBW) and other poor infant outcomes.

The three year averages (1996-1998) for Native Americans in Wisconsin were as follows: total # of births was 373

- infant mortality rate was 11.4 per 1000 live births while the rate for Wisconsin's general population was 7.0
- 46% women smoked during pregnancy compared to 18% for all races
- # of LBW was 17
- # of VLBW was 3
- # of preterm was 99
- # of births to teens 18 years and younger was 71
- # of live births to women entering care in first trimester was 246

The 1990 Census data for Wisconsin used at that time revealed that 46% of Native American children under the age of 18 lived in a family with an income below the Federal Poverty Level compared to 6.2% for all races. In the majority of the partnering tribal communities, there was no public transportation available for perinatal families. Despite the strength of tribal communities as a whole, many families were often stressed and overwhelmed about daily living issues, which contributed to low educational attainment, substance abuse, lack of parenting skills, and poor eating habits. According to Wisconsin's 2000 Maternal Child Health (MCH) database, the data system in use at that time, the average inter pregnancy interval for project clients less than 6 months was 24.2% and 6-15 months was 20.3%.

II. Project Implementation – Began with tribal contracts with GLITC for a second four year project period funded through the Healthy Start Initiative. Each tribe is a sovereign nation, with its own rights and ownership. Four tribes chose to be contractual sites, and four chose to be non-contractual sites. Non-contractual site staffs were GLITC employees. Contractual site staffs were tribal employees. All HOC site staffs worked under the policy and procedure of each tribe. Site staffs were supervised by the Health Director or other authorized personnel.

A. Outreach and Client Recruitment - The project's first focus was to get women into early prenatal care. The service system at the tribal level consisted of a health department, clinic and pharmacy. Most tribal health systems did not have a doctor on site, and referrals were made to nearby hospitals and clinics. The tribes did have a maternal child health (MCH) nurse among their clinical nursing staff. The MCH nurse would offer pregnancy testing which was an opening for referrals to the HOC project. This same nurse worked the WIC (Women, Infants and Children Supplemental Food System) clinic referring potential clients to the project. Outreach to tribal and non-tribal health agencies also brought referrals. Best of all were the referrals from project participants. They were quick to encourage new pregnant women to enroll in HOC.

Case Management - of the pregnant and post-partum women and their children to age two, immunizations, assessment and referrals would be provided by the tribal MCH/HOC nurse. Health clinic appointments and home visits enabled the nurse to do assessments and referrals. Barriers to care included inclement weather, unsuccessful home visits and missed appointments. Personal client issues as barriers included denial of the pregnancy, fear of confidentiality disclosure, and occasionally avoidance of medical care as pregnancy was considered a "natural occurrence" and not a "sickness". Challenges included rural health care issues with limited providers, barriers to access and limited resources. The project built on the strengths of the tribal communities and their desire to honor the children.

Health Education and Training - at the community and project participant levels would be implemented by HOC site staffs to increase community awareness of important perinatal issues and disparities in health and healthcare. WAIIMR outcomes were discussed at the tribal level with emphasis on prevention. It was important for families to learn about pregnancy, nutrition, healthy-lifestyles, birthing, breastfeeding and parenting. A tracking

component to gather data on project activities and outcomes was the state's MCH Data system at that time. Most of this was in place from the previous four year Healthy Start funding, and HOC at that time was known as Honoring Our Children with a Healthy Start. Health, safety and screening and assessment training for the site staff and MCH nurse assured clients and the project administration that the information was current and the staff well-trained.

Interconceptional Care - would focus on women between pregnancies up to two years or until a subsequent pregnancy occurred. This would be an ideal time to address health issues and encourage adoption of healthy life-styles. Contacts included informal meetings in the community, to formal contacts at hospitals, clinics, or by referral. Birth-control information would be an additional focus with these contacts. Care would be done by all site staff, including the MCH nurse.

Depression Screening and Referral – was a new focus under maternal child health services. Mental health issues were the domain of the AODA departments of the tribal health systems before this time, and referrals, when needed, were informally done between the nurse and the AODA provider. An acceptable screening tool was to be adopted and a formal referral system needed to be in place. The involvement of a screening by the MCH nurse was new, and the referral and follow-up (whether, or not, the client kept the appointment) would be tracked. Collaborations with off-reservation mental health providers needed to be addressed. There was a shortage of mental health providers and those that were available had waiting lists. Meetings with the tribal health directors, MCH nurses and site staffs, local mental health providers, and the Honoring Our Children Project Advisory Committee (PAC) – Title V and other agencies, would result in the successful implementation of this core service. The tool of choice was the Edinburgh Maternal Depression Screening tool, which had been developed in the United Kingdom, and adapted slightly to conform to the common language of the States.

B. The components of the intervention focused on pregnant and post-partum women and children to age two. Most women were identified as high risk; risk factors included smoking, and/or drug/alcohol use. Because the project was in its second four year cycle of funding from Healthy Start, HOC was a familiar and accepted program in the community, and families were more willing to participate.

The project sites were eight tribal reservations located in Wisconsin: Bad River Band of Lake Superior Chippewa, Forest County Potawatomi Tribe, Lac Courte Oreilles Band of Lake Superior Chippewa, Lac du Flambeau Band of Lake Superior Chippewa, Red Cliff Band of Lake Superior Chippewa, Sokaogon Band of Lake Superior Chippewa, Stockbridge-Munsee Band of the Mohican Indian, and the St. Croix Band of Lake Superior Chippewa.

The project design included 1) partial funding of the MCH nurse to do case management and prenatal care coordination, 2) the tribal hiring of a (FTE) on-site coordinator to promote collaboration and consortia building and community education, and 3) the tribal hiring of a (FTE) outreach worker to build trusting relationships with the families. The

families would then be inclined to be active participants in the project, and receptive to education and motivation to adapt healthy-lifestyles. The outreach workers were members of the community, familiar with tribal services and may have been a consumer of the health system in the recent past. These experienced outreach workers knew what the barriers were to accessing health care, and were able to assess each family's need, offering transportation, or the use of a phone to make an appointment, or offering support and information when needed. The outreach worker worked closely with the MCH nurse to coordinate care and education. The on-site coordinator supervised the outreach worker.

Referrals to HOC came from the MCH nurse who provided pregnancy test kits for the clinic, or through the WIC (Women, Infants and Children Supplemental Food program) clinic and the same nurse. Referrals also came out of project promotion in, and outside the tribal community. Best of all, program participants encouraged new pregnant moms to, "Sign up for HOC".

The on-site coordinator became very familiar with the local resources and worked to build consortia and collaboration with other tribal and non-tribal agencies. Partnerships between health programs delivered community education and activities with reduced costs and increased participation. Examples included, at one site, a partnership with Birth – 3 for Baby Olympics. This was a fun event where small babies competed for small prizes at a day long event with educational opportunities to increase awareness of health resources. Consortia members were local tribal leaders, health representatives and community members with an interest in maternal child health issues. They assisted with program planning at each tribal reservation, as each tribe had different concerns.

The project site offices were usually at the tribal health departments or clinics. One site was at a tribal building and later moved to a domestic abuse house. This location proved to be problematic. Program participants were reluctant to enter the domestic abuse house, and risk rumors starting that there was trouble in their family. Later, this HOC site would be moved to the health department for better access.

NEST incentives were provided to HOC participants for keeping appointments, getting their baby immunized, accomplishing goals, etc. These participants may not have been able to acquire these necessary and needed items, otherwise. NEST items could be baby blankets, thermometers, nursing bras, etc. Hammers, flashlights and screwdrivers were also in NEST to appeal to the male partners taking care of the families and who were active in HOC. Participants earned NEST points, which were then cashed in for the items.

The HOC Central Staff, housed at GLITC was responsible for development of PAC (Project Advisory Committee). This committee would guide the project in planning and sustainability. Membership included representatives of the local consortia, state health administration and other health agency representatives, HOC site staffs, tribal leaders, health directors, GLITC program staffs and HOC central staffs. For more information refer to the following section D.

Staffing difficulties arose at various sites, and corrections included tribal and GLITC/HOC consultations and cooperation. Some difficulties came about due to the professional/para-professional mix. Occasionally, a nurse would prove problematic or culturally inept at working with the families in the community. All staffing problems were resolved. Out of 17 site staff positions including the MCH/HOC nurses, twelve HOC staffers were with the program in the first four years, and continued into the second four-year funding cycle. These members were often the most valued and trusted by HOC participants and their children.

Other challenges include the rural nature of shortages of health services, health providers and isolated tribal reservations. Both the geography and Wisconsin weather with long winter months and deep snowfalls make access to health care and travel on rural roads more difficult. Many families were limited in their resources, and were without phones or a reliable type of transportation. Additional family stressors included poverty, under-education, discrimination, and lack of social resources.

C. Additional resources to the project came with two federal grants written by the HOC central staffs: 1) Rural Health Outreach, and 2) Health Disparities in Minority Health. This funding supported the project's goals and activities. The change in Healthy Start Budget from the first four-year cycle into the second cycle was \$104m to \$900,000. The Rural Health Outreach funding assisted with building collaboration with the non-tribal site providers and hospitals near two of the partnering reservations. The Minority Health grant supported an outreach worker at one site where there was only an on-site coordinator, a male having difficulty accessing clients with home visits. All sites but one had on-site coordinators, at the one site the supervisor had been a former on-site coordinator. Later at this site the outreach worker performed so well, she was advanced to the on-site coordinator position. Only four sites had outreach workers, in response to the reduced funding at the beginning of this second four year grant period. At one site the on-site coordinator is an LPN working under the supervision of a Nurse Practitioner.

The reduction of funding from one 4-year cycle to the next had ramifications for the project. Rumors began that HOC was not going to be around. This had a reactionary response by the community as government programs had come and gone many times, leaving tribes without services. Some site staffs became unsure of their employment, and this affected their motivation with the project. Some health directors lost confidence with HOC as well. It took years for HOC to recover from this funding dilemma.

D. Consortia Building

1) Local Consortia (tribal) – Responsibility for the establishment of a local consortium at each site was given to the on-site coordinator. The on-site coordinator was to be familiar with the local resources and collaborate with tribal and non-tribal health service providers for project planning. The plan was to combine tribal providers and consumers, tribal leaders, and elders for a comprehensive view and community impact for project planning. Each site was different with differing maternal child health problems and issues. How each community responded to their problems was the task of the local consortium with

the help of the HOC site staffs to address. Examples of collaborations with the community include: 1) One site's consortium thought it important to involve dads in learning more about pregnancy and child care.

Daddy Boot Camp was designed with cooperation and involvement of the Tribal Health Director, Tribal Chairman, Birth-3 Program Director, Day-Care Supervisor, Tribal Tobacco Program Coordinator, and tribal clinic. Dads had an obstacle course they had to maneuver while carrying and caring for a "Baby Think It Over" doll, that would present barriers to the final destination by crying, needing to be fed or changed, etc. Other barriers occurred during the journey through the obstacle course like "You lost your keys," "You have to go back and pick up the other children." Dads were very responsive to the day's events and said they learned more than they ever wanted to know about how their wives manage with pregnancy and child-care. It was very successful and the community asked that this be repeated next year. New HOC dads asked, "Are you going to have Daddy Boot Camp?"

At another site, the local consortium was concerned about cars driving too fast along the local highway; the speed limit and highway was in the main part of the community and presented a danger to the mothers and families. The consortium brought in the law enforcement, and learned how to change the speed limit to make it safer. Arrangements with the tribal council, the town and county municipalities were involved. The speed zone was reduced and families were in less danger from being hit by a car.

Another site's local consortium took on gang violence. Law enforcement officers, judges, tribal council, community members and tribal leaders were involved to solve this safety issue that affected the mothers and children and families. The local consortium empowered the whole community to take action and make a difference. Gangs were dissolved, and the community was safer for moms and children.

Project Advisory Committee (inter-tribal) – PAC was organized of members from each local consortium, Title V representatives, Wisconsin Public Health, Wisconsin Infant Death Center, Health Directors, Tribal Health and Human Services, University of Wisconsin Medical School, Even Start, UW Cooperative Extension, Marshfield Medical Research Foundation, Lincoln Hill School of Correction, GLITC/EpiCenter, Wisconsin Tribal Health Directors Association (WTHDA), and the Wisconsin Department of Workforce Development. This group of stakeholders is a wonderful resource for program planning and evaluation.

Linkages with PAC extend to: 1) the Maternal Child Health Advisory Committee (project manager is an active member), 2) the Northern Region Infant Death Center (project manager and local evaluator are active members), WTHDA (project manager reports on HOC activities), and Local Tribal Consortia (local evaluator attends meetings). Barriers - PAC and the local consortia were formed in the first four year funding period. PAC was developed smoothly, but the local consortia were problematic for site staff to establish. Tribal people were not familiar, and did not associate with the word "consortia". One site staff called their consortium "Maamawi Circles" instead of HOC

consortia meetings. The new name removed barriers to joining the consortium. Another problem was that the same tribal leaders being asked to join this consortium were very active on other committees. In small communities, leaders in the tribe are asked to help out in many ways. These are busy people with many commitments. The site staffs responded to this problem in several ways.

The on-site coordinator at one site joined a committee already formed and brought the HOC project concerns, activities and promotion to their table. This group was short on consumers, but the provider members had family who were consumers, and knew well the issues they faced in accessing healthcare. The on-site coordinator occasionally brought project participants to attend these meetings.

Efforts to keep local consortia a majority of native peoples is easily managed by the on-site coordinator at the tribal site. PAC has a slight majority of native peoples as the proportion of natives to white is smaller when utilizing non-tribal organizations throughout the state as members.

2) The local consortia are informal in structure, in keeping with the cultural focus. A healthy snack is provided, as well as transportation and child care. The time and meeting is determined by each consortium membership. The on-site coordinator usually leads the meeting and may be assisted by the outreach worker. An educational component is planned, followed by responses. Discussion turns to local issues to address specific problems or activities in the community. A sign-in sheet is managed by the on-site coordinator listing name, tribal site, individual's role (HOC staff, provider, HOC participant, community member, and other). We have not tracked by gender, but the majority members are female. The on-site coordinator keeps the notes of the meetings and the sign-in sheets. The activity is reported in their monthly reports to the local evaluator. The local evaluator, or other member of the HOC central staff, attends local consortia meetings if possible. The site staffs appreciate the support from the central staff, and the central staffs learn much more about the current tribal issues.

3) The activities these collaborations have utilized to assess ongoing needs include guests speakers from GLITC, the tribes and even the consumers. One consumer talked about the safe sleep and how hammocks were used to care for sleeping infants. Suggestions regarding accessing resources come from the tribe, the state and other outside influences. All are directed toward maternal child health issues. Resources are utilized and monitored by the tribe and GLITC. The HOC site staffs sit on other consortia/collaborative as well as the HOC central staffs.

4) The major strength of the tribal communities is the caring and respect each one gives the other. Native Americans are very resilient. They have withstood having most of their values attacked by the "dominant race". Agreements and contracts have been broken, land lost, families separated, language abolished and lifestyles forever changed. Being respectful, one would respond positively when someone is asked to participate on a

consortium. Plus, the community has many problems, and the answers are in the community.

5) A barrier to consumer tribal membership in PAC was reimbursement for their involvement. The project wanted to give the tribal members a cash stipend for their time and involvement to cover their costs. The funding agency said that wasn't allowed. We learned we could reimburse for lost time at work, and child care. So, a form was developed to document the participant's time away from work, and they would then be sent a check for that lost time; if child care was utilized, a Wal-Mart card was given.

6) Strategies to increase resident and consumer' participation, included giving NEST points at the local consortium level. Good food is served, which is very cultural. Educational components were interesting and relevant. Discussion on local issues were what the membership felt was important at each community. Publicity about the project, project activities, and one-on-one talks encouraged consumer involvement. All HOC families were invited to participate. Collaboration also included invitations to providers to join the local tribal consortium. Consortia building changed over time if the staff changed. Some site staffs were better than others at building consortia. We asked experienced sites to mentor those having problems.

7) Consumer input was encouraged to be part of the consortia discussion. Tribal members are more than willing to say how they think things should go. For instance, community members expressed concerns about pregnant women smoking and drinking. Elders expressed concerns over changing values, and how women are now required to leave their babies and go to work (Wisconsin Works Program – W-2). They were concerned that they do not see breastfeeding in the community like in the olden days. Many grandparents are raising their grandchildren with little resources. It is difficult, and all are concerned.

8) The consumer suggestions were utilized by planning for recommended changes. Examples were given in D-1. HOC site staff reported on their monthly reports and at PAC meetings, each site had an opportunity to report their activities to the PAC membership. The consortium may have had to address the tribal council with their issue. Outside resources, like law enforcement, or the judicial department needed to be consulted.

E. Sustainability

1) Managed Care committees are in place with several tribes. Usually these tribes are larger and more business skilled and successful. Smaller tribes have committees, but they are seldom utilized. Successful managed care committees work at assessing each family's medical case as to whether they can provide the care, and where to refer, if care is not possible. Plans work toward the best solution for care, and after care, at the best affordable price. Indian Health Service (IHS) pays for most of the tribes' medical care, and yet, they receive only \$.32 on the dollar. One case, costing many thousands of dollars can bankrupt a tribe's budget on medical care. It is a crisis.

Third party billing has been successfully done in a few tribes, and they have been doing this for a few years. Other tribes have difficulty with any success. Barriers to their success may have been staff turnover, or the complexities of the process. Paul Reynolds, of the GLITC/Indian Health Service has worked with the tribes to some extent, but the goal of having all tribes successfully billing has not been realized, after years of effort.

The HOC central staffs have consulted with the tribal health directors of the HOC projects to see if there was anything else that could be done to access states funds. Each tribe is different, and the problems are different. Some of the tribal staffs grow weary of submitting claims only to be returned as not satisfactory. Central staffs have also contacted Title V to discuss what can be done to make things move along. HOC has collaborated with the GLITC Rural Infant Health Program (RIHP), funded by state block grants, in having trainings for the MCH nurses to coordinate prenatal care coordination and billing. RIHP also hired a private consultant who had experience working on the state site of these funds. The consultant worked with a few tribes for a short period only as she had prior commitments.

Each site's problems are unique and need to be handled with one-on-one training and consultation. Even when this is done, staff turnover results in a need for repeat training in third party billing. It is an ongoing problem. The HOC/RIHP training was a temporary fix. Whether successful or not, the resources are reimbursed to the tribes, not the HOC project. With the shortage of IHS reimbursement, there is little opportunity for third party billing going to the HOC project.

2. Major factors associated with the identification and development of resources to continue key components of the HOC intervention without HS funding are the tribes and PAC. The tribes have been appreciative of the good outcomes related to HOC including: increased utilization of tribal and non-tribal health facilities through support services of transportation, referrals, phone usage for appointments, increased case management, immunizations, reduced smoking/alcohol/drug use, and self-reported consumer increases in healthy lifestyles. Some tribes provide for in-kind space, phone, and printing costs. The tribes are good about contributing when the HOC site staffs are planning something special. But the tribes are in no way able to support the program's operations. Site staffs also write funding requests to support their NEST items.

The HOC central staffs continue to look for federal, state and foundation funding to carry on the good work of HOC. Tribal and non-tribal agencies contribute to HOC by co-funding educational activities. As an example, a program at one site funded by a diabetes grant works with the HOC staff to plan an educational event about diabetes. The diabetes program has the extra funding, and the HOC program has the family contacts. Collaboration extends funding with good outcomes for all.

Site staffs and central staffs work at finding and writing grants to continue the sustainability of the HOC project through federal, state and foundation grants. Our site staffs have become very good at procuring local support from businesses including the tribe's. They shop for NEST items at end of season sales, and write letters for donations.

The tribes donate space, printing, phone, etc. differing at each site. They become very supportive of the project and help out where they can. Money is in short supply for everyone. The tribes also face major health disparities; they have elevated infant mortality, suffer from chronic conditions such as diabetes, heart conditions, asthma, obesity, etc. They have the characteristics of a community that is the focus of major research and public health initiatives. Yet, IHS and the tribes are limited in their resources. Grant opportunities will surely remain the major factor associated with the identification and development of resources to continue this successful project. HOC served only eight of the eleven tribes associated with GLITC. Non-HOC tribes are interested in partnering with GLITC and deserve the services HOC tribes' experience. Current HRSA funding does not cover HOC and additional funding is necessary. Federal funding should reward successful projects and look to expand their success.

3) There is a perception that gaming has made tribes wealthy, and they do not need further funding. The truth is that while some tribes have become successful, many tribes are poor from lack of sufficient gaming due to poor location and enterprise. Tribes face many issues, and funding, if available, goes to reduce the poverty, under-education, unemployment, etc. of the families it serves. HOC continues to educate and inform outsiders of the true conditions of the tribes it serves.

III. Project Management and Governance

A. The structure of the project management which was in place for the majority of the project's implementation consists of Great Lakes Inter-Tribal Council, Inc. a consortium of eleven federally recognized Indian tribes in Wisconsin and Upper Michigan. The organization was chartered as a non-profit, non-stock corporation under Wisconsin law, and is incorporated as a non-profit corporation. All of its board members are tribal members, who are current members of the community which GLITC serves. Founded in 1965, the purpose of GLITC was to provide a means by which member tribes could unite against the threat of termination. Today, the GLITC mission has evolved to support member tribes in expanding self-determination efforts by providing services and assistance. GLITC uses a broad range of knowledge and experience to advocate for the improvement and unity of tribal governments, communities and individuals. Throughout all its activities, GLITC maintains deep respect for tribal sovereignty and reservation community values. The organization bridges the gap between recognizing the individual sovereignty of each tribal community and the cooperative necessity of reaching shared goals, such as those addressed by this project. GLITC believes that the separate sovereignty of each tribe must be honored, and we do so by not interfering with Tribal affairs while addressing common needs. Current members of GLITC include:

- Bad River Band of Lake Superior Chippewa Indians
- Lac Courte Oreilles Band of Lake Superior Chippewa Indians
- Lac du Flambeau Band of Lake Superior Chippewa
- Red Cliff Band of Lake Superior Chippewa
- Sokaogon Chippewa Tribe (Mole Lake)
- St. Croix Chippewa Tribe
- Forest County Potawatomi Community

- Oneida Nation
- Stockbridge-Munsee Band of the Mohicans
- Menominee Tribe of Wisconsin
- Lac Vieux Desert Tribe (Michigan)

Although Lac Vieux Desert Tribe is located in Michigan, the Tribe is a GLITC member because of its geographical proximity to Wisconsin, just over the border in Upper Michigan.

The Honoring Our Children Project is in the Family Health department of GLITC, supervised by Elaine Allen, GLITC Deputy Director. The GLITC/HOC central staff consists of Alice Soulier - Director, Barbara Stoddard - Manager, Cindy Weborg - Fiscal Assistant, Laverne Oestreich - Local Data Evaluator, and Christine Friedrich - Administrative Assistant.

Tribe	On-site Coordinator	Outreach Worker	MCH/HOC Nurse
Bad River	Linda Lemieux		Michele Graves
Forest County Potawatomi	Missy Flanery		Jodie Harris
Lac Courte Oreilles	Tiffany Nielsen		Janel Larson
Lac du Flambeau		Christine Zortman	Julie Wondrasek
Red Cliff	Melonee Montano	Rose Gordon	Erin Tenney
Sokaogon	Teri Hunt		Amy Franti*
St. Croix	Kathleen Dittmar		Linda Benton
Stockbridge-Munsee	Harold Katchenago	Elisa Kasbob	Debbie Safford

The tribes supervise the site staff and the staffs work under tribal policy and procedures. The Health Director or designated employee is the supervisor for the on-site coordinator. The on-site coordinator supervises the outreach worker.

B. Tribal Accountants working with the HOC project assured that fiscal activities were handled well and bills were paid in a timely manner. Bad River – Bonita Green, Forest County Potawatomi – Christine Craw, Lac Courte Oreilles – Norma Ross, Lac du Flambeau – Sandy Allen and Bernelle Young, Red Cliff – Diana Erickson, St. Croix – Sharon Nelson, Sokaogon – Myra Vanzile, and Stockbridge-Munsee – Carolyn Miller. These site accountants worked with Cindy Weborg, HOC’s fiscal assistant to make sure the tribal nurses were paid, and the HOC budgets were in keeping with recommendations.

C. The changes over time for management and governance that occurred included the change from the state’s MCH data system to the SPHERE data system. The system was not available till about one year after it was scheduled to be ready. Not only did the staff need to learn the new system, but they had to re-enter all the data from the months after the MCH system was closed and the new system started. This was a hardship for the staff, and for the tribes as well since staffs needed time to catch up on data entry at the cost of salary or participant contacts.

Another change that occurred during the 4 year funding cycle included the HOC Director, Alice Soulier (formerly Elm) and her appointment to the Lac du Flambeau judicial court as a judge. This was an honor, and expressed the respect and position Alice held in the community. Alice was available to our staff at a moment's notice for program operations. She continued to attend grant conferences and kept in communication with grantors. Alice was, and is, an important part of the negotiations between the tribes and GLITC, and is best serving the project as a member of the tribe of Lac du Flambeau, and Native American.

D. Experience and wisdom affected the process developed to assure the appropriate distribution of funds over time. All tribal sites differ, as expressed previously. Some sites were small and locally situated, some were large and locally situated; some were large and spread out into communities more than 20 miles apart. Expenditures differed in community needs. Some sites needed more funding for transportation; some needed more funding for supplies and a larger population, but having tribal transportation available. Over time, funding became more efficient based on need.

E. GLITC resources proved to be essential in working with the tribes. The GLITC accounting department assisted with audits, program compliance, budget management, and contracts with the tribes. The GLITC/IT (Information Technology) Department helped with the tribes in their internet connections, helpful for communications. The GLITC programs – Tobacco, Birth to Three, Birth to 21, Vocational Rehabilitation, AIDS, Family Nutrition, and Elders' programs all complemented the activities of the HOC project. The GLITC EpiCenter provided statistics necessary for program application and assessment. Local tribal agencies were helpful to HOC through wonderful collaborations as already expressed under Consortia Building D1.

F. Cultural competency of project staff becomes an issue when non-native staffs do not understand the cultural element. This became a problem with a nurse at one site. The HOC project manager worked with the HOC site staff and their supervisor to help, but eventually, that nurse was replaced. Non-native staffs have a harder time winning the confidence of the HOC families unless they have lived in the community many years, and are accepted. These non-natives may not draw as many participants to project activities without the collaboration of a native staffer. Cultural competence is a learning experience that comes with time. It is important that HOC staffs know the families of the communities they serve and are respectful and accepting of their cultural differences.

IV. Project Accomplishments

A. The major strategies implemented, with its goals and objectives and accomplishments follows. Please refer to the Final Report Implementation Plan, Appendix A. Baselines and Data Sources are included in the table only.

1. CM4 By 5/31/05, the Project Advisory Committee consortium will have met quarterly each year with 50% Native American representation, 25% consumer members, and a consumer participation score of 60%.

Accomplishments: As of 12/31/04, the PAC met quarterly, with 53% (19/36) consumer members, and 67% (24/36) of the members attending at least half of the meetings. In addition to the PAC in 2004, 4 of the 8 tribal sites had local consortia.

Description: The PAC was very instrumental in project planning and sustainability. It was important for the site consortia members to be involved with the state, university and health agency PAC members, to hear what each group was planning and doing to address infant mortality and health disparities in the state. Both groups had a better understanding of each other, and the education and training experienced through PAC enriched the cultural component and the current status of health and well-being in the state.

Barriers: Community participants from the local consortia were self-intimidated by the important representatives from the state, etc. at PAC. The site staffs were helpful in reassuring them that they were important to the discussion and the PAC was a friendly and welcoming environment for discussion. Their children were welcomed if child care was not possible. Good food was served, and good discussion was experienced by all on serious perinatal issues. Transportation was provided by the HOC sites staffs. Reimbursements for lost pay and child care were provided to the tribal participants. The PAC survey indicated that PAC members were satisfied with the project and its planning.

2. 02 By 5/31/05, project staffs will recruit 75% of the population of perinatal women and 75% of infants up to age two years.

Accomplishments: As of 12/31/04, the project served 84% (357/423) of the population of pregnant women, 50% (237/476) of the population of postpartum women, and 88% (538/608) of the population of infants up to age two.

Description: Referrals and canvassing the service area by the HOC site staffs worked well to identify woman and their children to participate in the project. Because the project is well accepted in the community, word of mouth referrals work well. Home visits and a special relationship developed project participants to be active with the project.

Barriers: Some women are reluctant to join groups due to lack of family support. Others may not participate due to abuse of alcohol, drugs or smoking choice, and denial.

3. CM2 By 5/31/05, 85% of participants will initiate prenatal care in the first trimester of pregnancy.

Accomplishments: As of 12/31/04, 82% (210/255) of pregnant participants initiated prenatal care in the first trimester. [Note: Underutilization of the new SPHERE system resulted in 29% (102/357) of pregnant women with missing data that were excluded from this analysis.]

Description: Getting women in early for prenatal care is most important to the plan. Outreach and recruitment are major activities initiated by the site staffs. Referrals through tribal and non-tribal agencies promote participation in the project early in pregnancy. Word of mouth is another referral that accomplishes project participation.

Barriers: Data collection in the new SPHERE system resulted in missing data, although, the trend for the project indicates increasing rates of accomplishment for this goal. Early initiation surpasses the state's 2003 data showing 71% initiated care and HOC rate is 80% in 2001, 84% in 2002, 80% in 2003 and 82% (with under reporting due to SPHERE) in 2004.

4. {2.3.1} By 5/31/05, 95% of pregnant and 95% of postpartum women and their infants will receive case management.

Accomplishments: As of 12/31/04, 89% (319/357) of pregnant participants and 74% (382/518) of interconceptional women and their infants received case management.

Description: The tribal MCH/HOC nurse was responsible for case management. The nurse worked closely with the HOC site staffs to accomplish this goal with prenatal care coordination and a wide range of health and social services. Weekly meetings assured that no one was missed. Education and support services reached everyone.

Barriers: Some women are reluctant to participate in project activities due to their use of tobacco, alcohol and other drugs. This has remained a barrier to care, and the site staffs gently include them in all invitations to participate, offering support without judgment or criticism. Some women are from dysfunctional families who do not join groups. The site staffs continue to invite and encourage these women. Reports of eventual participation are received well by all project staffs.

5. CM1 By 5/31/05, 92% of participating infants up to two years of age will receive the full schedule of age-appropriate immunizations.

Accomplishments: As of 12/31/04, 85% (308/363) of infants up to age 2 received the full schedule of age appropriate immunizations.

Description: Immunizations are important to the well-being of the infant. The project works hard to get families in for the "baby's shots". Transportation assists with this goal as families have unreliable transportation at most sites.

Barriers: Some families are difficult to reach and don't comply with the immunization recommendations. Persistence and the reward of NEST points are helpful motivations. The rates of immunizations for HOC sites are higher than the 2003 statewide rate of 81% for all Wisconsin infants.

6. CM3 By 5/31/05, among women who prenatally receive project services, the percentage of Low Birth Weight infants will be less than 5%, of Very Low Birth Weight

infants will be less than 1%, and of preterm infants will be 7%, and of Small for Gestational Age will be 3%.

Accomplishments: As of 12/31/04, 3.3% (8/243) infants were low birth weight, 0% (0/243) was very low birth weight, 7.0% (17/243) were preterm, 1.6% (4/243) was small for gestational age, and 9.1% (22/243) were large for gestational age. There were two infant deaths.

Discussion: Very low and low infant weights are not, major problems with this populations, although some Native infants are born too soon, and may suffer from increased immaturity at birth.

Barriers: Smoking may be responsible for premature births in this population, and the project works hard at encouraging reduction or elimination of smoking and second-hand smoke in the environment.

7. {2.1.8 & 2.1.9} By 5/31/05, of project participants, 75% of pregnant and 75% of postpartum women and 25% infants will be identified as high risk.

Accomplishments: As of 12/31/04, 68% (244/357) of pregnant participants, 32% (75/237) of interconceptional participants, and 37% (199/538) of infants were identified as high risk. [Note: Underutilization of the new SPHERE system resulted in missing cases, including 27% (97/357) of pregnant participants, 63% (150/237) of interconceptional women, and 24% (131/538) of infants.]

Discussion: Most women in the service area are identified as high risk.

Barriers: Missing data in the new SPHERE system was a problem.

8. CMT3 By 5/31/05, 95% of postpartum women will receive interconceptional services

Accomplishments: As of 12/31/04, 75% (177/237) of all postpartum participants received interconceptional services.

Discussion: Most of the interconceptional HOC women were reached by the HOC site staffs. Participant retention in the project may account for these contacts. Continuing educational contacts on matters of healthy lifestyles may positively impact a woman's health and the health of her next child.

Barriers: SPHERE system adaptation resulted in missing data. This problem will be resolved by next report. Barriers of reluctance to join, has been referenced previously.

9. CMT2 By 5/31/05, 75% of case-managed perinatal women and 75% of case-managed infants will have completed referrals.

Accomplishments: As of 12/31/04, 81% (154/189) of the tracked referrals for perinatal women and infants, including 81% (105/130) of the referrals for pregnant and interconceptional women, were completed. [Note: A total of 2,097 referrals were made, but only 9% (189) were tracked for follow-up, due to underutilization of the new SPHERE data system.]

Discussion: The HOC site staffs are responsible for referrals and follow-up. Follow-up includes support for the family undertaking the action required with the referral. This is based on the trust relationship established early on by HOC staffs.

Barriers: Contacts are not always possible due to the rural nature of the area, and the lack of phones in HOC houses. The sites staffs report more than 50% of HOC families are without phones. Underutilization of SPHERE was a problem. The local evaluator worked to help staff adjust with the implementation of the new system, and its delays.

10. CMT4 By 5/31/05, 100% of case-managed infants with Special Health Care Needs will have completed referrals.

Accomplishments: As of 12/31/04, 100% (7/7) of the referrals for infants with special health care needs were completed.

Discussion: All infants with Special Health Care Needs have been referred and have completed those referrals. The HOC sites staffs work closely with the GLITC/B-3 and county programs that service these children. HOC staffs continue family support after the referral process.

Barriers: There are no barriers for this objective.

11. {2.1.15} By 5/31/05, 95% of project participants will be screened for depression.

Accomplishments: As of 12/31/04, 30% (176/594) of perinatal women were screened for depression. [Note: Not all of the screening was documented due to underutilization of the new SPHERE data system.]

Discussion: Women are screened for depression at least two times by the MCH/HOC nurse, once in pregnancy and once post-partum.

Barriers: Screening was a new endeavor for this project period. Previous mental health problems were the responsibility of the tribal AODA or mental health provider alone. The MCH nurse only referred, and did not screen. Now all HOC women are screened and a formal referral system has been put in place by the HOC project. SPHERE entry was a problem. Central staffs encouraged tribal support of HOC staff in this area.

12. CMT2, {2.1.11} By 5/31/05, 95% of participating women who screened above the threshold for depression will be appropriately referred to mental health services. (Formerly Objective 9.)

Accomplishments: As of 12/31/04, 22% (38/176) of the women who were screened were referred to mental health services. [The SPHERE data system does not include the information needed to determine the percent of women who were referred for mental health services among those who screened above the threshold for depression.]

Discussion: If the mother's score indicates a referral is necessary, the nurse and the client plan on the referral and the location of choice by the mother in agreement with the plan.

Follow-up by the MCH/HOC nurse and site staffs include support services.

Barrier: Adaptation to the SPHERE system resulted in not all the referrals being entered. Follow-up contacts are continued after referral whether the client keeps the appointment or not. The staffs continue to encourage keeping a referral appointment.

13. ET1, C1 By 5/31/05, health education sessions will be provided to 100% of project staff, 96% of participating families, and 60% of consortium members, and there will have been 200 education contacts to service providers.

Accomplishments: As of 12/31/04, health education was provided to 100% (27/27) project staff, 71% (461/650) of participating families, 94% (178/190) of consortium members, and there were 787 education contacts to 427 service providers.

Discussion: Health education is done both at a project participant and at a community level. Collaboration with other tribal and non-tribal health agencies combines the effort to reach all families in the service area. Education is part of the PAC meetings as well. HOC stays current with issues of perinatal care and brings this to the table for discussion and planning. Families have expressed a desire to learn more and do more. They indicate satisfaction with the educational activities. These activities are done in a passive way, in keeping with the culture. Beading classes or craft classes encourage consumer participation and exchange while absorbing an educational component on health.

Barriers: Consumer reluctance to participate is overcome with the award of NEST points and a healthy snack. Transportation and promotion of the activity is the responsibility of the site staffs. Newspaper articles advertise activities and promote participation.

14. ET2 [New] By 5/31/05 75% of participants receiving health education in smoking cessation will decrease or stop smoking.

Accomplishments: As of 12/31/04, 51 perinatal women smokers received smoking cessation education and 51% (26/51) decreased or stopped smoking. Outcome data were missing for 29% (15/51).

Discussion: Smoking is a cultural activity under spirituality. The ascending smoke brings the prayer to the creator. Education on the hazards of tobacco chemicals and second-hand smoke is done at the consumer level and the community level.

Collaboration with GLITC Smoking Cessation project helps with this difficult adjustment for Native peoples.

Barriers: Women who smoke have friends and family who believe that smoking does not harm the children. Education has helped some families relate the health problems of their children now, to the hazards of smoking and second-hand smoke. Many households now have a sign at their door, NO SMOKING - BABY HERE. Native Americans have a very high rate of smoking. It is an ongoing problem with evidence of change on the way.

15. ET2 [New] By 5/31/05 75% of participants receiving health education in substance abuse, self reported lowered frequency or elimination of this risk behavior.

Accomplishments: As of 12/31/04, alcohol use during pregnancy was documented for 31 women and illicit drug use before pregnancy was documented for 40 women. Health education in substance abuse prevention and/or referrals for treatment were documented for 22 women. 50% (11/22) of the women, who received health education/referrals for substance abuse, self-reported lowered frequency or elimination of this risk behavior. Outcome data were missing for 45% (10/22).

Discussion: HOC works hard at changing women's lifestyles into healthy ones. Alcohol and drug abuse is used in response to the stressors and impact of life's problems. Encouragement and support from HOC site staffs to quit, really is making a difference. It is an ongoing problem.

Barriers: Shame and avoidance are apparent with some women and their families. Reluctance to join groups and participate comes with use and abuse. Support and encouragement can reach many women, and the HOC site staffs work hard at making a difference. SPHERE system adaptation resulted in missing data.

B. The GLITC Honoring Our Children Project received no mentoring during this project period.

V. Project Impact

A. Systems of Care:

1. Collaborative activities happened at the tribal and non-tribal level. The on-site coordinator was familiar with the native and non-native health systems in the project service area, and worked at forming a collaborative at the local tribal level. A representative of this local coalition was then invited to become a member of the HOC/PAC to come to the table and discuss perinatal issues with state health department staffs, university and managed care facilities. This enhanced the effectiveness of communication and project planning at the inter-tribal level, as well. Collaboration took place at the family or consumer level in a different way.

Collaborative approaches were the responsibility of the on-site coordinator at each site. The on-site coordinators were responsible for developing a list of resources, both tribal and non-tribal, in the service area to meet the needs of the HOC

families they served. Families face many hardships and they need resources to help them resolve their problems. The on-site coordinator was helpful in developing a collaborative of agencies, both tribal and non-tribal that surpassed the focus of perinatal health. Problems that families face were in areas of safety, education and schooling, job placement, judicial systems, Indian Child Welfare, housing, law, etc. The on-site coordinator, familiar with these agencies would be able to refer the families to the appropriate agency for help with finding a job, getting back to school, checking the water for safety, and more. HOC was truly a help to many families who were trying to access care. Follow-up to these referrals was part of the over-all comprehensive service of HOC staffs.

2. Structural changes established for the purpose of system integration can best be described by the establishment of a formal referral system for maternal depression. Before HOC the referral system was very informal and no tracking was done. During the second year, the tribal and non-tribal consortium assisted in identifying an appropriate screening tool for maternal depression to be utilized by the HOC/MCH tribal nurse. Then, local mental health providers joined PAC and gave voice to the need for a formal referral system. They were very pleased to see this take place. The HOC Central staff worked with the tribal health directors, local mental health providers and HOC site staff to put into place a formal referral, and feedback system that would be tracked on the SPHERE system.

The SPHERE (Secure Public Health Electronic Record Environment) replaced the states MCH data system that was connected with the WIC data system dAISY. The HOC data evaluator, Charlanne FitzGerald, from the University Department of Population Health Sciences, Wisconsin Public Health and Health Policy Institute was instrumental in working with the state in the development of the system to answer data requirements to assist program reporting.

Structural changes also included the moving of an HOC site out of a domestic abuse house under the supervision of a previous on-site coordinator, and into the health department under the supervision of the health director. Housing at the domestic abuse house prevented the easy access to care needed for the HOC families. Some moms did not want to be seen entering the abuse house for fear that rumors would be started. The supervisor at the abuse house was not responsible for collaboration building, and this left the site with only an outreach worker and an MCH nurse for project activities. Central staffs worked with the tribal council and the health director to make the move to a more productive environment welcoming mothers, children and fathers without fear of false rumors. The tribe's policy was to house the HOC project at the health department. The outreach worker was a volunteer from a GLITC vocational rehabilitation program to assist the MCH nurse with HOC family's activities. She was so very successful, that she was promoted to on-site coordinator and, combined with a new nurse at the new site, proved to have a real turnaround for collaboration, education and care.

3. Key relationships that have developed as a result of Healthy Start efforts are:

- a. Collaboration with the Wisconsin Infant Death Center's Director, Anne Harvieux, has brought critical information on Sudden Infant Death Syndrome and safe sleep to the tribes and HOC participants. Anne's program has also been helpful in conducting a grief workshop for our HOC site staffs so that they may be skilled in helping families who have experienced infant death.

PAC member Rachelle Ashley, with the Wisconsin Department of Workforce Development, kept HOC families applying for state subsidized programs abreast of important issues surrounding Food Share, Employment and Training (both conducted from two different offices); and TANF (Temporary Assistant for Native Families) programs.

She keeps us abreast of legislative and programmatic issues pertaining to families directly, such as the following:

- When the funding for the Quality Kids child care was voted down and restored through competitive grants developed by the governor.
- The joint legislative committee voted a 15% increase in child care co-pay which resulted in more out of the pocket expenses for families in Wisconsin.
- Funding for payment of domestic violence and sexual assault related exams has been cut which leaves the victims to rely on third party payers.
- Eligibility for W-2 and other public assistance programs must be at 185% of poverty income level.
- Some tribes set up a "Navigator" to assist families in understanding the various programs.

Greg Nycz, from the Marshfield Medical Research Foundation and PAC member has been helpful to the HOC project and tribes by alerting us to the availability of grants for community-academic partnerships to promote the goals of Wisconsin's health plan, Healthiest Wisconsin 2010. The Wisconsin Partnership Fund for a Healthy Future is based on the premise that community-academic partnerships capitalize on the strengths of community-based organizations and of the UW Medical School faculty and academic staff. The HOC Central staffs are initiating plans to apply for this funding.

PAC has been the most influential project activity that has developed relationships between the tribes, families and the state. Our family representatives were nervous about coming to GLITC and sitting among professionals from the state and university, yet through the

course of the meetings, they have become confident that they have something to share, their experience, and viewpoint is important.

b. The HOC project started seven years ago with focus groups consisting of a young couples group and an elders group. We asked them what programs were they aware of, what programs did they use, which programs did their extended family use and what they thought of the tribal health systems of yesterday and today. HOC involved the tribal members and community leaders because they are the most experienced and know the community better than anyone. Their voice matters. Knowledge gleaned from those original focus groups helped with program planning and had advantages over local providers and even health directors on what the issues were for each tribe from the prospective of the consumer. It was most helpful. As mentioned earlier, most providers working with tribal agencies are members of the community and have grown up in the service area, familiar with what's available.

4. Impact of HOC services.

a. HOC has had input in the development of intake forms, referral and feedback forms, and an increased awareness of health and social services in the community and off-reservation. HOC central staff and the RIHP have worked with the state to make user friendly intake forms for the prenatal family questionnaire to reduce repeating questions to the consumer as they move through the health-care system. Referrals to social services or health programs made it easier for the consumer to be moved into specialized care when needed. The HOC project enhanced the comprehensiveness of services by the project and the agencies, working in collaboration through referrals. Agency representatives reported increased access due to the support services provided by the HOC site staffs.

b. Barriers to access and service utilization and community awareness of services were affected by the HOC project. In rural areas where the tribes are located, lack of transportation is a major barrier to access. If the family has a car, it may not run. If the car runs, there may not be childcare. High-risk moms in early focus groups reported their referral to off-reservation providers for high-risk care. Moms attempted to drive, but it cost money for gas they didn't have. There was no one to watch the children if she left, so she didn't continue with the appointments. HOC families may have phones, but they may not be connected. Job loss through health problems may limit their resources to keep up the cost of a phone. The HOC outreach worker makes sure the mom can use a phone to make and keep appointments. The on-site coordinator can help families get connected to programs that help, but they need a phone or transportation to initiate the participation. HOC helps. Families share

what they learn through HOC referrals and more families understand that there are programs that can help.

c. HOC site staffs have improved the quality of care by initiating the link between families and healthcare through the services of site staffs. Having a para-professional, trusted tribal member a mother can talk to is critical at times. Emergencies find family members calling the HOC site staff for help and assistance. Calls also invite staffs to participate in joyous occasions of birth and celebrations of achievement (quitting smoking, breastfeeding beyond one year, etc.). The car ride is a safe, confidential place where secrets of domestic abuse are shared. Private information about medical conditions or symptoms of sexually transmitted disease is made possible to share by the trusting relationship between the site staff and the mother. Site staffs make the transition to care easier, bringing a hesitant, but more confident, active participant along. After a referral, the site staffs keep in touch with the mother and her progress, encouraging her with contacts, good words and sincere praise.

d. The tribal MCH/HOC nurse enters patient information into SPHERE and clinic files. Immunization records between the clinic and HOC are shared. Clinic providers do not access SPHERE, but work with the MCH on patient care coordination. At one site the MCH nurse is also the nurse for the doctors that work in that clinic, and she enters information into clinic patient charts as well as SPHERE. The HOC families are usually on WIC. Previous to SPHERE, the data was shared on the state's MCH data system. The WIC data system at this time is not connected to SPHERE, but connecting a new WIC data system to SHPERE is in the state's plan for the summer of 2005.

5. HOC has involved the participants in project evaluation at the tribal level and the inter-tribal level.

a. HOC site staff pledge to keep confidential all matters of HOC participants. This pledge carries over to discussion between health providers as well. In small communities, it is very important to not have conversations about clients in an insecure location. A HIPPA standard of compliance is very important. Even well-meaning providers must be always alert to casual conversation about clients that may be inappropriate. The clients must trust the HOC site staffs and nurse with confidentiality. Providers must regard confidentiality, customs, beliefs, and values of the clients as sacred. A special effort to draw men into the system of maternal child health care is made by the HOC site staffs as men want to know all they can about pregnancy and child care. This was revealed in the early focus groups. Men wanted to be included, informed and taught to have skills necessary for support of their partners and the children they would parent. They wanted more information about

healthcare costs and insurance, why the women have mood swings and how to work with them, and more.

b. Consumer participation in educational activities included a mechanism to evaluate if the program activity was successful. At first, this was not successful. In Indian country, it was considered disrespectful for you to ask if they learned anything. Through gentle explanations, and reassurance that the staffs were interested in their comments, project participants were more likely to complete a post-test. Most sites do not utilize these as they are not culturally appropriate. As part of the program evaluation, HOC participants were helpful in sending their satisfaction or not to the evaluator in a confidential manner to assure a feeling of trust. The HOC project received very good evaluations and the participants appreciated the services the project offered. Many testimonials included even life saving outcomes for the families through car seat safety checks, and CPR trainings. Consumer feedback helped the project streamline forms and make entrance into care easier.

B. Impact to the Community:

1. Residents knowledge of resource/service availability, location and how to access these resources increased with the on-site coordinators' resource listings. This knowledge has empowered participants and community members to take action in affecting change in families and in the community, toward good outcomes in pregnancy, birthing, breastfeeding and parenting.

During this 4-year funding cycle, four of five annual Families Helping Families Gatherings took place. The first conference was held in 1999. This was a collaboration of the two Wisconsin Healthy Start Projects – the Milwaukee Healthy Beginnings project and the GLITC Honoring Our Children project. Families from two very different geographic areas shared their values, customs, food, spiritualism, and resources in navigating the health care system in Wisconsin. 77% of the FHFG family participants reported that they were able to gather very much or quite a bit of new information at the conference. 89% reported that very much or quite a bit of what they learned will be helpful. Overall, 56% rated the gathering as excellent and 40% rated it as good. (Wisconsin Health Disparities And the Families Helping Families Gatherings, C.J. FitzGerald, Center for Health Policy and Program Evaluation, UW Medical School) More information about the Family Helping Families Gatherings can be found ahead in C. "Impact on the State".

2. Consumer participation in the local consortia empowered families to address real issues of care, safety and concern in their tribal communities. In section D on consortia building, descriptions of how the consortia dealt with speed limits on highways, gang violence, inclusion of fathers in education and training, and more. This encouraged participation of the families because they could see results and

their concerns were satisfied with positive outcomes. Their actions involved providers, local governments and the tribes that ended with positively affecting the health and welfare of the community.

3. Native Americans are normally very respectful to each other and to outsiders, especially when elders are present. When someone speaks at a meeting, no one interrupts. Each person's words are respected. While one might disagree, respect was shown to each other and conflicting opinions were resolved without a problem. Team building is culturally appropriate with Native Americans. They are familiar with working toward a common goal – the welfare of the tribe. As children, they learn that the tribe is the whole. Each person has a place or a job to do in the tribe, for the betterment of the tribe. By working together they learn each other's talents and skills. "This is what the creator planned for them to do."

4. Jobs were created through the HOC project in the community. HOC site staffs were hired by the tribes within the community for on-site coordinators, and outreach workers, as well as, nurses; even though the number of Native professionals was small in each community. HOC participant educational sessions were successfully done when a craft was incorporated into the session and healthy food was provided. Native bead makers were hired to teach beading on baby moccasins, while information about pregnancy, birthing or breastfeeding was discussed. Food was prepared and served by a community member and this created jobs paid for by HOC.

C. Impact on the State:

Collaboration between the two Healthy Start projects in Wisconsin resulted in truly unique annual 2-day conferences named the (Annual) Families Helping Families Gathering (FHFG). For five years, Healthy Start families from urban Black, Hispanic, and Hmong communities met with, came to know, and befriended the rural Native American families in northern Wisconsin. For the first meeting, the urban families traveled "up north" to GLITC to meet and develop the intent of the conferences. Many of these families had never traveled so far, and especially had never been on a reservation before. They had many questions. The conference was planned and delivered by the families; the Healthy Start staffs merely assisted with their arrangements. The families chose the conference focus and were the guest speakers.

The audience was composed of "professionals" – state public health, legislature, and universities members. Families shared their values, customs, resources and stories of learning to access the healthcare systems successfully and being resilient. The families learned they had much more in common than the high infant mortality/morbidity rates they shared. They had "spirituality" and "extended family" that carried them through discrimination, poverty, unemployment and prejudices. Funding prevented further conferences after the 5th annual FHFG held in 2003, but they were very successful in empowering

families to succeed, and demonstrating that families wanted to be more knowledgeable about healthcare.

The FHFGs addressed disparities in Wisconsin, offering a consumer perspective. These urban and rural families had a history of adversity, a social environment of racism, classism, poverty, under-education, stress, and lack of social capital. They had a disproportionately high number of low birth weights, premature infants; they lacked appropriate prenatal care, and suffered from higher rates of diabetes, cancer, asthma, heart disease, and AIDS than whites living in the state.

They suffered with their physical environment and carried a genetic endowment linking them with disease and poor health. Disease effects were accelerated by stress. Access issues included 1 month waits for appointments and 2-3 hour waits for 5 minute visits in Milwaukee. Families believed that people with health insurance versus Medicaid got better care. There was a shortage of dentists that serve low-income families; inadequate interpreter services, and experienced providers and people with “attitudes”.

Suggestions from the families included:

- People have a right to understand the process and be treated respectfully.
- Have a good relationship with your caseworker.
- Keep asking questions.
- Have someone come with you. “When the nurse goes with the family, they are treated differently.”
- Ask for a supervisor. “If something sounds unreasonable, it probably is.”
- “It’s good to argue with your doctor.” Be an advocate for yourself and get a referral.
- Parents are a key partner in making health decisions for their children and themselves.
- “People who challenge the system always do better than those who don’t.”
- Call the American Medical Association, Legal Action, or your State Representative.
- Poor people have to work together. Talk about these problems with friends and family.
- Target physicians who treat minorities and serve on committees so you can influence them.
- Become more involved in your community and the electoral process.
- Become activists.

Suggestions for the state program planners included:

- Have ongoing outreach, on the radio, free crisis hotlines, door to door, flyers, mailings, phone calls, and present at schools.
- Be responsible, keep informed, and check resources.
- Cover costs of medications, glasses, hearing aids, and teeth.
- Have people from the community as workers.
- Become oriented to the culture, provide interpreters.
- Make home visits.
- Make sure moms get early prenatal care, get to their appointments, and get to well-child checks.
- “At the Tribal Clinic, you call one person and they find out what you need.”

Conference workshops included: Identifying local resources for families, threats of the system, healthcare conditions that impact people of color, good job preparation strategies, financial planning and home buying, dealing with abuse, preparing for a new baby, breastfeeding stories, parenting skills, parenting and nutrition, mental health and depression, domestic violence, teens become parents, fathers are parents too, tobacco and our culture, movement for health, that directly impacted the families.

The FHFGs were supported in part by HRSA Healthy Start Initiative, GLITC/HOC project, Black Health Coalition of Wisconsin – Milwaukee Healthy Beginnings Project, Wisconsin MCH Title V Program, Wisconsin Association for Perinatal Care, and the Marshal & Isley Foundation, Milwaukee, Wisconsin. Donations also came from: the elders from Lac du Flambeau, GLITC projects including Rural Infant Health Project, and Elders Program.

The relationship between Title V and the two Healthy Start projects in Wisconsin has been very good. With Title V participation with the FHFGs, they became better informed about the barriers to care that families face. They learned that their spirituality was a driving force in their resiliency and needs to be a respected element in their representation. One really needed to participate in a FHFG to understand what a truly enriching experience it was.

Activities with the state MCH Advisory Committee resulted in more comprehensive outreach to Children with Special Health Care Needs programs both tribal and non-tribal. The HOC site staff works closely with referrals to the GLITC B-3 Program, Birth -21 and VRNA. Follow-up after referrals is in place through the MCH/HOC nurse, and HOC site staffs for family support. With increased information from the MCH Advisory meetings the tribes are more aware of state services including Medicaid and SCHIP programs. Many tribes have benefits specialists that help the families access these programs if eligible. The HOC site staffs make sure that families have an appointment with these helpful co-workers at the sites.

D. Local Government Role:

Relationships at the state level have been very successful with HOC. The relationship that was developed with Title V through Dr. Richard Aronson has continued with Dr. Murray Katcher, his replacement as Chief Medical Officer. Dr. Aronson understood the cultural values of the Native Americans and was missed when he left for another position back east where his family was from. Dr. Katcher volunteers his time at tribal clinics several times in the year. He is familiar with our HOC sites and can speak of them from his working with the health providers, and serving the families in the communities.

The HOC project manager serves on the state's MCH Advisory Committee working on the sub-committee for cultural competence. Issues of perinatal outcome are of a major importance to the committee and the expertise of the committee persons is comprehensive in dealing with the state's health concerns. At a stakeholders meeting a list of the problems/needs were developed:

At a stakeholders meeting a list of the problems/needs were developed:

- Infant mortality
- Contraceptive services
- Low birth weight
- Unintended pregnancy
- Infant and early childhood mental health
- Dental caries
- Access to healthcare for children
- CSHCN receive care within a medical home
- Health insurance coverage
- Tobacco use among youth
- Child abuse and neglect
- Smoking among pregnant women
- Adolescent mental health
- Teen births
- CSHCN have adequate insurance]
- 1st Trimester medical care
- Overweight and at risk for overweight
- Intentional childhood injuries
- Women's mental health and depression
- Unintentional childhood injuries

The HOC project manager also served on the steering committee for a state-wide 2003 summit conference, "Healthy Babies in Wisconsin – A Call to Action".

This conference looked at identifying evidenced based practices that were working to reduce the state's infant mortality, and addressing the state's perinatal health disparities. A PPOR (Periods of Perinatal Risk) tool was utilized to help regions of public health, urban settings (Milwaukee) and Native Americans (Wisconsin tribes) to use birth data to reveal the highest risk to mothers and their infants. For Native Americans the data revealed that the highest risk was in Maternal Care and second highest was Child Health. A Native American

workgroup discussed this information and developed a priority list to focus their activities: 1) Smoking, 2) Breastfeeding and 3) Social Issues. While there was no money to support continued meetings with this workgroup with membership from across the state, they do meet yearly at the Native American / Department of Public Health conference in the fall at a pre-conference meeting to discuss evidence based practice.

Barriers to care in rural areas include a shortage of providers and long distances to high risk care facilities. Barriers from a consumer's perspective, is listed in the previous section C. under FHFGs report.

E. Lessons Learned:

The lessons learned include the failure to adequately explain, with the accomplishment in changing attitudes of - how the tribes are sovereign nations; how some tribes can become successful with gaming, but not all tribes are; that families can live in poverty in spite of gaming, that outsiders cannot come in and "fix things".

VI. Local Evaluation – follows the Narrative.

VII. Fetal and Infant Mortality Review (FIMR) - NA

VIII. Products

The GLITC/HOC project produced a curriculum that encompassed the 8 tribes and the educational materials they use for consumers in their communities. Each site is different and the methods included more than one type of educational component. This product is used internally and has not been made available to outside providers.

IX. Project Data – Project Data forms follow Local Evaluation