Healthy Start Native Peoples Council

Position Papers on Maternal and Child Health
Among American Indians and Native Hawaiians

March 2005
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Speaking With One Voice

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Healthy Start Native Peoples Council:
A Consortium of Healthy Start Projects Serving Indigenous Families

Aberdeen Area Tribal Chairmen’s Health Board: Northern Plains Healthy Start
City of Minneapolis: Twin Cities Healthy Start
Great Lakes Inter-Tribal Council: Honoring Our Children Project
Inter-Tribal Council of Michigan: Maajtaag Mnoobmaadzid (A Start of a Healthy Life)
State of Hawai’i Department of Health: Malama A Ho’opili Pono Healthy Start Project
University of North Carolina at Pembroke: Healthy Start CORPS

For more information contact: Inter-Tribal Council of Michigan, 906-632-6896, www.itcmi.org
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Miigwetch, Mahalo. Pilamaya. Thank you.
This report represents the unified voice of the Healthy Start Native Peoples Council. This Council emerged from a very powerful gathering of six federally funded Healthy Start Programs, which address infant mortality in Native populations. The event, the Healthy Start Indigenous Peoples Summit, took place in 2003. This gathering of the Healthy Start projects that serve and in many cases are guided by Native people, was historic and ground breaking for those of us who work within this vital initiative.

We have all heard the mantra of respect and support for cultural diversity over the years. From a Native perspective, we have often been on the sidelines, and so this has not always happened to the degree necessary to affect and impact lives or to make policy changes. Indigenous populations are smaller in numbers and often have no “face” to the larger society. In Hawaii our face is frequently shown as entertainment for the tourist industry. For American Indians it may be the Pow Wow. I wonder how many would know the American Indian or Hawaiian people without that frame or other trappings that have identified us? Of course we love our music, dance, and traditions, but also want these to be understood in the proper perspective and with the proper respect.

A group of us within the Healthy Start family began talking about our needs and uniqueness with respect to federal services several years ago. As we talked, it became very evident that we have many similarities in perspectives and traditions. We look to our ancestors, those gone before us, for continued guidance. Spirituality, not religion, permeates much of the life of Native people and traditional protocols for living are still followed in many cases. We also know that we have great disparities among our people, that one size does not fit all, and that there is also great diversity among us.

A very wise Hawaiian elder once said, “health is how you live your life.” We do not separate and compartmentalize bits and pieces of us but “live” together in our body. Body, mind and spirit are one and whole together. If a part is hurt or ill then the whole is also. We must be in harmony with Akua (God) and the land. We have great elder wisdom yet we see that many around us do not hear this wisdom. This for us is a great disparity. Much more is needed to bridge and heal the years of existing in a “separate” way. Living in pieces has taken its toll on all of our people. Many of the Native people are disconnected and living lives of despair, yet traditions and beliefs are rich. The statistics portray an unsettling and disturbing picture including higher rates of incarceration, school dropouts, unemployment, chronic disease, poor birth outcomes and more.

We appreciate the federal mandates and dollars that target racial and ethnic disparities. In order for these mandates to make a difference, however, there must also be an acknowledgement and honoring of traditions and practices regarding the way that business is accomplished in our Natives communities. Everyone is in a search mode—researchers, federal agencies, states, and
even local governments—in a search for the magic bullet, model or cultural fix that can be replicated and solve the problems. If only it were that simple.

We, as responsible Natives and people working with Native projects, including non-Natives, must take this responsibility seriously. Together we must identify and then support those cultural practices that are also cultural determinants of health that make a difference for us. How do we weave and then strengthen that cultural safety net or blanket that will cloak and care for our people when needed? How will we use traditions to make a difference in service delivery and learn to adapt and modify when necessary? How can we support people to live successfully in both Native and Non-Native worlds? These are important questions. These position papers present an opportunity for us to walk our talk. And they are also a call to action for Natives and non-Natives alike—policy makers, program funders, health administrators, service providers, and community activists—to fulfill our responsibilities to all mothers, babies and families in this country.

We have a vision of healthy and thriving Native peoples for generations to come. These position papers include recommendations, which are steps along the path to improve maternal and child health for Native communities. We hope we will all work together towards this end.

Mahalo.

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Healthy Start CORPS
Executive Summary

“One size does not fit all...we have unique Native populations with unique needs.”

Healthy Start Indigenous Peoples Summit
Executive Summary

“So Creator sent a Peacemaker with a message to be righteous and just, and make a good future for our children seven generations to come.”

Great Law of Peace, Haudenosaunee Confederacy, Six Nations Iroquois

In order to build an effective, equitable and sustainable healthcare system for all Americans we must first evaluate how things actually work and how we wish them to work differently. For Native and indigenous people nationwide (American Indians, Native Hawaiians and Native Alaskans)\(^1\), how things actually work within the healthcare system is not optimal. In the Institute of Medicine’s recent landmark treatise entitled “Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare,” the opening paragraph states:

Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patient’s insurance status and income, are controlled. The sources of these disparities are complex, rooted in historic and contemporary inequalities, and involve many participants at several levels.

Racial and ethnic disparities in infant mortality have been consistently documented in the United States but the causes of these disparities are poorly understood. The rates of infant mortality and SIDS for American Indian and Native Hawaiian babies are alarming—in some cases as much as four times higher than rates for white infants. In order to better understand and untangle the complex web of inequities, in February 2003 the Healthy Start Native Peoples Council (HSNPC)—a consortium of Healthy Start Projects serving indigenous families nationwide—convened a conference entitled the “Healthy Start Indigenous Peoples Summit.” The goals of the summit were to: engage in cultural exchange by exploring similarities within indigenous cultures; explore disparities and key issues related to perinatal health status of Native people; share success stories regarding workable strategies in Native communities; identify opportunities for educating policymakers; and communicate summit findings to the larger world. The summit featured a broad spectrum of participants from six regions in the United States (see map, back inside cover) including Healthy Start clients, Native elders, Tribal health planners, federal government representatives, nurses, outreach workers, midwives, nutritionists, social workers, academicians, indigenous healers and spiritual leaders, and healthcare administrators.

\(^1\) The indigenous people of North America are typically referred to as American Indian/Alaskan Native/ Native Hawaiian, and though distinctly different from one another, they all share some of the same disparities in health status as compared to the White population. This report was inspired by the Healthy Start Indigenous Peoples Conference in 2003, which did not include Native Alaskans simply because there were no Healthy Start Projects in Alaska. Therefore we cannot speak to the issues impacting Native Alaskans in this report without their explicit representation. This paper addresses maternal and child health issues facing American Indians and Native Hawaiians, and in this paper, those two groups are referred to as “Native or indigenous people.”
The purpose of this report is to explore the nature of maternal and child health disparities among our nation’s Native people; to report on the lived experience of health disparities in Native communities; to propose recommendations for organizations working with or designing programs for Native people; and to advocate for systems change in local, state and national policy-making arenas.

Healthy Start, a federal initiative of the U.S. Maternal and Child Health Bureau (MCHB), was inaugurated by Congress in 1991 and is committed to reducing infant mortality and improving the health status of high-risk mothers and infants by granting funds for maternal and child health (MCH) programs to at-risk communities and populations. Nationwide, there are currently over ninety Healthy Start projects; six Healthy Start (HS) projects specifically target Native people. Healthy Start’s vision is to create the best community-based, community-driven approach to infant mortality reduction. Healthy Start’s key strategies are case management and interventions that are specifically tailored to each distinct community.

In designing and implementing MCH programs that work for Native families, it is critical that Native people are brought to the table as planners, are involved in project leadership and implementation, and are included in monitoring and evaluating the success of programs in their communities. Otherwise—as is the case with many existing healthcare programs that target Native people—programs will be off the mark, and thus, ineffectual and underutilized. In addition, program interventions must incorporate culturally honored therapies for healing and Native strategies for health promotion.

This booklet is a collaborative effort that emerged from the 2003 Summit data as well as from follow-up meetings and teleconferences. It has been created, reviewed, and edited by a diverse membership from the Healthy Start Native Peoples Council. Four position papers have been developed with specific recommendations aimed at educating, empowering and mobilizing people. It is our goal to bring all stakeholders into the circle as partners in addressing disparities in maternal and child health among Native populations and other minorities, and “to make a good future for our children seven generations to come.”

An overview of Healthy Start Native Peoples Council Position Papers:

Position Paper 1: Reducing Barriers and Increasing Access to High Quality, Culturally Competent Maternal and Child Health Care for American Indians and Native Hawaiians: In order to ensure access to effective high quality healthcare for Native populations and for all Americans we must aggressively pursue changes in the way maternity care is designed and provided across the nation. It is shortsighted to think that we can solve access and quality of care dilemmas without making substantive changes to our present healthcare system. Significant barriers to accessing care for Native communities are: poor geographic distribution of goods and services; discrimination in the delivery of health services; lack of trust in existing systems; and socioeconomic factors. Strategies for increasing access to providers and services include: utilizing holistic and culturally competent healthcare models and practitioners; ensuring that
Native people are at the helm of programs in their communities; endorsing universal access to healthcare; and improving the healthcare workforce. In order to decrease barriers, increase equal access to service delivery, combat disparities in maternal and child health status, and fully engage Native people, our present maternity care system requires restructuring. Access to an equal standard of healthcare for all Americans and models of care that are effective and satisfying will strengthen our nation and ensure its well being for future generations.

**Position Paper 2: A Model That Works! Healthy Start Projects Serving American Indians and Native Hawaiians:** Healthy Start is a community-based maternal and child healthcare (MCH) model that is succeeding where other programs have failed with Native populations. Healthy Start is uniquely positioned to address racial and ethnic disparities experienced by Native people (such as higher rates of infant mortality, poor birth outcomes, and sudden infant death syndrome); to give voice to inequities in the health care system (such as racism and discrimination in the allocation of healthcare goods and services); to support the development of innovative, holistic and culturally appropriate strategies to address risky behaviors (such as high rates of smoking, poor dietary practices, alcohol and drug use, and violence); and to put Native people at the helm of educating the public, addressing gaps in services, and eliminating disparities within their own communities in partnership with community-based and statewide consortia. Healthy Start, as experienced by many Native people, is a model in developing best practices and effective interventions. In addition, Healthy Start programs seek to combat racism, discrimination and unequal treatment, and as such, are agents of social justice within healthcare arenas.

**Position Paper 3: Partnership in Progress: Strengthening the Relationship Between the Federal Government and Indigenous Communities in Maternal and Child Health Efforts:** American Indians and Native Hawaiians are among the indigenous peoples of the United States. These populations have a unique relationship with the federal government because of their special history of being dispossessed of their ancestral lands and associated social systems. Geographic displacement and implementation of overt policies aimed at eliminating their social organization, language and culture had a profound effect on the Native peoples of this country and resulted in multi-generational trauma which is a key underlying factor behind the poor health status of modern indigenous communities. The U.S. government has a special government-to-government relationship with Tribes and a distinct and direct responsibility to provide for the health care of the indigenous people of this country. This special government-to-government relationship is affirmed in numerous treaties, statutes, and executive orders, as well as legal, moral and ethical principles. Likewise, federal legislation affirms the special responsibilities and legal obligations of the federal government to the indigenous people of Hawai’i. Indigenous groups are hampered by a lack of visibility, and recognition of their health issues. Native leaders are calling for greater attention and responsiveness from federal partners. Often despite language in official documents which affirm the eligibility of Native and Tribal organizations to participate in federal initiatives, policies and programs are not structured or administered in such a way as to facilitate participation by indigenous groups or to be relevant in a Native community.
setting. Intervention models and required components of federal programs tend to reflect a “one size fits all” mentality, and although Native representatives may often be invited to provide input into federal planning and review processes, it has been experienced in many cases, that decisions have been predetermined and their input is ignored.

**Position Paper 4: Supporting Maternal and Child Health Data Collection and Research Agendas That Include American Indians and Native Hawaiians:** Racial and ethnic disparities in healthcare exist; they are consistent and extensive; they exist for all minority populations including American Indians and Native Hawaiians; and they are associated with poorer health outcomes. There is the potential for reliable research to enrich our understanding of how to improve the quality of care and health status for special populations, and ultimately improve the health of this nation’s people and its communities. Indigenous groups are hampered by a lack of visibility, and recognition of their health issues. Much of this “invisibility” is attributable to a lack of data. Racial comparison data very often lumps statistics for American Indians in with a wide variety of other groups into the racial category of “Other”, often a synonym for “too small to worry about”. Data for Native Hawaiians is often reported under the category “Asian and Pacific Islanders”. Because there is such disparity between Asian Americans and Native Hawaiians, and there are smaller numbers of Native Hawaiians, their worse health indicators are minimized by being combined with the relatively healthier Asian groups. Existing vital records and public health surveillance systems do not adequately or accurately provide basic demographic and health outcome statistics for indigenous populations. Discrimination continues to exist when Native people are not adequately or accurately represented in data collection, program planning and policy development for their communities.

**Healthy Start Native Peoples Council—Recommendations for Action:**

**Position Paper 1**

1. The U.S Department of Health and Human Services (DHHS) should increase access to high quality healthcare for Native populations by creating incentives to improve geographical distribution of healthcare providers and facilities where Native people live—in rural, isolated, island, and urban areas of the nation; and States should increase Medicaid reimbursement to healthcare providers willing to work in underserved areas.

2. The federal government—and all state and local entities who receive federal healthcare dollars for maternal and infant healthcare—should undertake restructuring of the perinatal system so that decentralized, community-based MCH models, that provide the best of modern medicine blended with complementary and integrative strategies, become the gold standard in maternity and women’s health care in Native communities. Allowable costs in these programs should include culturally focused preventive and therapeutic interventions.
3. Medicaid-funded programs should be restructured to preferentially fund models of healthcare that are holistic and family-centered, such as those that promote and support breastfeeding as a health promoting, life sustaining traditional practice, and the midwifery model of care. Evidence-based outcomes indicate that midwives are the primary MCH providers in countries with the lowest infant mortality rates in the world; midwives provide safe and satisfying care at a fraction of the cost of physician-based medical models.

Position Paper 2

1. Congress should enact legislation to make Healthy Start a permanent federally funded program (similar to Head Start and WIC) in order to establish it as an essential community-based healthcare service for at-risk American mothers and infants.

2. State public health departments, MCH agencies, and educational institutions should develop official policies and earmark funding to create opportunities for recruitment, education and career development to increase the number of Native professional staff.

3. Maternal and child health programs that use federal and state dollars should be culturally competent. To ensure this level of competency, federal agencies should give preferential points to MCH grant proposals that can validate that they serve Native communities, have Native Advisory Boards, are managed by Native leadership, have Native staff at all levels of project management, and have MCH programs that utilize cultural interventions and health-promoting strategies geared towards Native clientele.

4. Maternal and child health programs that use federal and state dollars should address women’s comprehensive needs across the lifespan and not be framed solely within the context of reproductive function. MCH programs should reflect the social, economic, cultural and political contexts in which maternal and child health occur by expanding MCH services to meet the needs of target populations.

Position Paper 3

1. Congress must fund the Native Hawaiian Health Care Improvement Act, the Native Hawaiian Education Act, and the Indian Health Service to full capacity, and work to fulfill treaty obligations regarding healthcare provision to America’s indigenous populations. The specific recommendations to Congress, the Indian Health Service, the Centers for Medicare & Medicaid Services, and the Department of Health and Human Services issued in 2004 by the U.S. Commission on Civil Rights should be fully implemented. At the State level, Title V Maternal and Child Health Block grants should include health indicators and program funding aimed at addressing disparities within Native populations.
2. The U.S. Department of Health and Human Services (DHHS) must improve its partnerships with Native populations by ensuring that its Tribal Consultation policy is fully adhered to by all departments. All DHHS departments should ensure that adequate American Indian and Native Hawaiian representation is involved at key policy and decision-making levels especially when developing new grant opportunities and setting eligibility and program component requirements.

3. Federal and State funding should be made available for programs that feature comprehensive and integrative healthcare interventions, and Native-specific traditional healing and health promoting practices, such as breastfeeding support, must be acknowledged and included as allowable program costs.

Position Paper 4

1. Federal agencies including the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Department of Health and Human Services (DHHS) should encourage collaboration with academic partnerships by requiring that all federally funded research projects involving Native populations include substantial roles for Native people as full partners in the research process, and provide training and support for this involvement as appropriate. Training programs and leadership opportunities for Native people engaged in health research should be expanded.

2. Federal agencies including the National Center for Health Statistics and the CDC, as well as State vital records and statistical bureaus should review standards for reporting of race. Changes at the State and local levels should be required that will allow for more accurate collection and compilation of health data on American Indian and Native Hawaiian populations, including collecting data on tribal affiliation. Additionally, tribal health authorities should be given the same access that local county health department have to birth and death certificate data and files for their service population. Whenever possible, appropriate statistical methods should be used to contend with small numbers in order to yield Native specific data, rather than reporting under the racial category “Other”.

3. The CDC, NIH and U.S. DHHS should expand research opportunities and design project parameters so that small indigenous groups with limited resources in staffing, technology and funding can participate. These opportunities should include support for the higher costs and greater complexity involved in conducting research in indigenous communities that encompass vast and remote geographical areas.
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Reducing Barriers and Increasing Access to High Quality, Culturally Competent Maternal and Child Healthcare for American Indians and Native Hawaiians

“Relationships and trust are paramount... and the quality of care and love that providers have is an important or more important than their credentials.”
Healthy Start Indigenous Peoples Summit
Despite having the most extensive and expensive maternity care system in the world, the United States still has inadequate and inaccessible care for our most vulnerable populations of women and infants. The U.S has invested inordinate amounts of resources in the past three decades to develop a cadre of specialty physicians and advanced technology for maternity care, yet we rank 28th in the world in infant mortality.\(^1\) Racial and ethnic disparities in maternal and child health status exist for most minority populations the United States. For example, in some areas of the country American Indian babies die at a rate that is two-to-three times higher than the rate for White American babies; the incidence of Sudden Infant Death Syndrome (SIDS) is as much as four times higher.\(^2\) Native Hawaiian babies die at a rate that is three times higher than the rate for White American babies; the incidence of SIDS is two-to-three times higher.\(^3\) The reasons for disparities are complex and not well understood. However, it appears as though lack of access to good quality care for mothers and infants, based on race and ethnicity, plays a significant role. In addition, lack of access to the kind of healthcare that is required to satisfy diverse populations, namely culturally competent care, is also a key issue.\(^4\) It is shortsighted to think that we can solve access and quality of care dilemmas without making substantive changes to our present healthcare system.

In order to address disparities and restructure the healthcare system so that it is equitable, accessible, and acceptable for all Americans, we must honestly assess how things are and envision how we want them to be different. To do just that, the Healthy Start Native Peoples Council—a consortium of Healthy Start projects serving indigenous families nationwide—convened a remarkable summit in 2003. The purpose was to gain a better understanding of how things are for Native people, to brainstorm solutions for improving access to maternal and child healthcare (MCH), and to propose strategies for effective programs for Native communities. Summit participants examined both barriers and strategies for increasing access to high quality care. Traditional “talking circle” and “talkstory” data gathering formats were used to identify the predominant themes. The barriers to good healthcare included: discrimination in health service delivery; socioeconomic factors; lack of the trust in the healthcare system; and poor geographic distribution of healthcare goods and services. Strategies for increasing access to high quality care included: utilizing community–based programs that provide holistic, culturally competent models of care; making certain that Native people are at the helm of MCH program design and implementation for their communities; ensuring universal access to healthcare; and improving the healthcare workforce.

**Barriers to Accessing Care**

1. Discrimination in service delivery
Even when taking socioeconomic factors into account, race and ethnicity remain significant predictors of the quality of healthcare a person receives. In 1999 Congress requested that the Institute of Medicine (IOM) examine the kinds and quality of healthcare received by racial and ethnic minorities. The taskforce identified a growing concern that racial and ethnic minorities have access to a lower quality of health services than non-minorities. The report noted that racial and ethnic disparities in healthcare occur in the context of broader social and economic inequality, both historic and contemporary, that persists in many sectors of American life. The IOM report focused part of its analyses on the clinical encounter itself and found evidence of stereotyping, bias and unequal treatment. The Healthy Start Native Peoples Council found that clinical encounters are often poorly matched to Native peoples’ needs. While some people reported that their providers were simply unfamiliar with cultural norms, beliefs or values, which made health encounters unsatisfactory or disappointing, others reported that they experienced outright racism or discrimination in clinical encounters.

2. Socioeconomic factors
While the perinatal systems that serve Native families vary within communities across the nation, like other minority populations Native people are less likely to have health insurance, have more difficulty getting healthcare, have fewer choices in where to receive care, and are often dissatisfied with the care they do receive. Socioeconomic data indicate that one third of all American Indians live below poverty level and half of all children live in poverty. Nearly twenty percent of Native Hawaiians live below the poverty level. The burden of poverty and unemployment puts private healthcare out of the reach of most Natives. In most of the indicators of health status and quality of life, including morbidity and mortality, Native people fare substantially worse than people of the majority culture. In addition to restricting access to healthcare, poverty and other conditions of everyday life influence risk behavior. Alcoholism, drug abuse and violence are significant problems for Native families resulting in increased rates of mental health problems, depression, accidents, injuries, suicides and homicides. In addition, Natives have a disproportionately higher rate of Fetal Alcohol Spectrum Disorder (FASD), and Sudden Infant Death Syndrome (SIDS).

3. Lack of trust in the system
There are two levels at which Native people do not trust “the system.” The first level has to do with experiences that are specific to indigenous people:
- loss of freedom and dispossession of ancestral homelands;
- collapse of traditional cultural systems and cultural assimilation;
- loss of hundreds of traditional Native languages nationwide;
- loss of traditional diets and access to affordable traditional foods;
- suppression of indigenous religion and medical practices;
- experience of inter-generational trauma and grief; and
- unfulfilled government-to-government treaty agreements.

Because of the historic and contemporary oppression experienced by indigenous people, there is often a reluctance to engage with the conventional healthcare system and/or a preference for utilizing traditional cultural healing systems.
Regarding the second level, many Native people do not trust that they are receiving good quality care from “the system.” Healthy Start Native Peoples Council reports that the current medical model of maternity care is perhaps the least effective and satisfying model of MCH care for the average American Indian or Native Hawaiian client, except in some high-risk situations. The Inter-Tribal Council of Michigan conducted a statewide perinatal systems analysis and found that perinatal systems in Tribal areas are inadequately meeting the needs of American Indians in fundamental ways. American Indian women and men are reporting them to be impersonal, fragmented, inconvenient, discriminatory, and neither community-oriented nor culturally competent. Of equal concern, Native people in a variety of regions of the country report difficulty in finding providers who will care for them in their first trimester of pregnancy. 

It is reported that lack of trust in the system, on both levels, constitutes a significant barrier to care and often leads Native people to disengage from or under utilize existing MCH services and providers.

4. Geographic Challenges
Native people live in cities, on reservations, on islands, and in frontier territories of the nation. However, those who live in rural areas are typically isolated from medical centers where comprehensive services are offered. They generally lack access to perinatal specialists such as obstetricians, gynecologists, pediatricians, neonatologists, and perinatologists. Rural communities generally lack access to specialty care facilities such as Neonatal Intensive Care Units, perinatal emergency care and surgery, and high-risk pregnancy facilities. Rural communities often lack access to universal 911 emergency services. For many Native communities, people even lack access to family practice physicians or mid-level providers such as nurse-midwives or nurse-practitioners.

Geographic barriers to care come in many forms. Hawai’i is comprised of seven inhabited islands with the majority of services and populations located on Oahu. While there is an on-going shortage of OB providers on the Big Island, even more critical is the lack of access to tertiary care on any island other than Oahu. For many Native Hawaiians, air travel and an overnight stay on neighboring islands is required for specialty care visits. American Indians living in the Upper Peninsula of Michigan must travel up to 500 miles to access perinatal specialists or high-risk facilities, which often necessitates crossing Lake Michigan on the Western Hemisphere’s longest expansion bridge and traveling to urban centers where services are offered. Treacherous weather conditions can make travel very dangerous. In North and South Dakota, Native people must drive for hours across long expanses of remote territory—the distance of several Eastern States combined—in order to access basic well-baby care and immunizations. In Wisconsin, and southeast North Carolina, as in many rural areas, families may have to drive two hours or more to receive specialty obstetric and pediatric care.

Because many Native families reside in rural and frontier America, the likelihood that mainstream outreach efforts reach these families is remote. Families may never have information about or access to health coverage meant to target uninsured, low-income
Native children such as the State Children’s Health Insurance Programs (SCHIP) or WIC (Women Infant and Children).

Because of distances, services often lack continuity. Fragmentation of services can be complex and confusing requiring families to seek services—such as WIC, Medicaid, clinical care, childbirth education, immunizations—at different locations, often at distances from one another. The challenge of geographic distance plus transportation difficulties makes for a problematic equation for Native families to tackle.

Strategies for Increasing Access to Care and Engaging Native Clientele

1. Provide holistic, culturally competent, community-based models of care

It is well documented that early and consistent prenatal care has an impact on reducing the risk of infant mortality and morbidity. But the big challenge is not only making healthcare accessible, but also making it acceptable. Native people report that they prefer holistic models of healthcare that involve all aspects of body, mind and spirit and service providers who are sensitive and respectful of cultural beliefs and practices. Examples of this kind of provider are lactation consultants and midwives, who have been identified as preferred practitioners because of the model of care that they provide, which is characterized as being “high caring and low tech.” Midwives are primary maternity care providers in countries that have the lowest infant mortality rates and their psycho-social model of care is based on the fact that pregnancy, birth and breastfeeding are normal life events, which are consistent with most Native traditions.

Native people also want spiritual healers from their own communities to be integrated into the healthcare team because they provide time-honored traditional practices for pregnancy and birth. For example, a Native healer may very effectively promote the inclusion of highly nourishing foods such as berries, greens, grains and tonics in a pregnant woman’s diet by teaching about their traditional medicinal properties and uses. She or he may be present during a woman’s labor to provide blessings for a safe birth, or may be present shortly after the baby is born to conduct a welcoming ceremony. Native people say that, “relationships and trust are paramount…and the quality of care and love that providers have is as important or more important than their credentials.” To Native people, spiritual health is an integral part of overall health. In addition, Native people are typically oriented towards the entire family, and their communities are often seen as extended families. For Native people, culturally competent healthcare models involve families and communities as integral to healing strategies and health promotion.

In order to improve pregnancy outcomes and strengthen family relationships comprehensive care must be provided to childbearing families that incorporates the emotional and cultural aspects of childbearing and childrearing. Healthcare models that are community-based, holistic, culturally competent, and family-centered, such as Healthy Start, are more successful in meeting the physical, spiritual and social needs of Native people where contemporary healthcare systems have failed. Healthcare systems must be restructured to incorporate these elements to fully engage Native participation.
2. Support Native people to be at the helm of maternal and child health programs
Native people must be central to the inspiration, design, implementation, and evaluation of MCH programs in Native communities. This includes increasing the number of Native people within the ranks of health professions, increasing the utilization of community outreach workers, and increasing Native administrators, researchers and program evaluators.

Native people say that, “One size does not fit all. We have unique populations with unique needs. Spirit and culture woven together is what defines Natives differently.” Programs must include these parameters if they are to be truly comprehensive and successful in both delivery approach and desired outcomes. If we are to get beyond simply acknowledging disparities to applying interventions that work for Native people (and other minorities), cultural knowledge must be put into action.

3. Endorse universal access to care
There are a number of strategies to ensure universal access to care. First, we must improve geographical distribution of providers and healthcare facilities for Native people and all people. We must ensure availability of maternity care providers on islands and in remote and rural areas of the nation. Second, we must improve access to high-quality insurance plans and to Medicaid. We must increase Medicaid reimbursement to providers willing to work in underserved areas to guarantee access to early and regular prenatal care and a continuum of women’s healthcare. These providers should include advanced nurse practitioners and nurse-midwives, practitioners who typically work with underserved clientele. Third, we must provide clients with education on how to effectively access healthcare and provide empowerment training for consumers regarding decision-making about their own health. Fourth, we must examine how healthcare is organized, regulated and financed and make changes to provide equitable standards for all. And last, we must endorse social justice as the guiding principle in the creation and implementation of healthcare and enforce healthcare laws as they relate to human rights.

4. Improve the healthcare workforce
There are a number of strategies to improve the pool of health professionals. First, we must address service providers’ level of cultural competency and sensitivity in order to improve communication and strengthen relationships between clients and service practitioners. We must provide cross-cultural education and training for all medical students, midwives, nurses, childbirth educators, and maternity care professionals. Second, we must increase the proportion of underrepresented racial and ethnic minorities in the healthcare workforce. This strategy alone has the potential of improving quality and increasing access to care for minority populations. Third, we may consider offering economic incentives to service providers who demonstrate improvement in client-provider communications, trust and interactions. And last, we must insist on a diverse workforce, not only racially but also across disciplines. We must make collaborative models the gold standard—a blending and balancing of traditional, conventional, and complementary practitioners and strategies.
Conclusion
It is shortsighted to think that we can solve access and quality of care dilemmas without making substantive changes to our present healthcare system. The current maternity care system—that is physician dominated, technologically complex, focused on monitoring and machines, and hospital based—has failed to recognize that pregnancy and childbirth are social as well as physiologic events, and are family-based miracles in progress.

In order to decrease barriers, increase access to quality care, combat disparities in maternal and child health status, and fully engage Native people, our present maternity care system requires restructuring. Access to an equal standard of healthcare for all Americans and models of care that are effective and satisfying will strengthen our nation and ensure its well being for future generations.

The Healthy Start Native Peoples Council recommends the following action steps:

1. The U.S Department of Health and Human Services (DHHS) should increase access to high quality healthcare for Native populations by creating incentives to improve geographical distribution of healthcare providers and facilities where Native people live—in rural, isolated, island, and urban areas of the nation; and States should increase Medicaid reimbursement to healthcare providers willing to work in underserved areas.

2. The federal government—and all state and local entities who receive federal healthcare dollars for maternal and infant healthcare—should undertake restructuring of the perinatal system so that decentralized, community-based MCH models, that provide the best of modern medicine blended with integrative strategies, become the gold standard in maternity and women’s health care in Native communities. Allowable costs in these programs should include culturally focused preventive and therapeutic interventions.

3. Medicaid-funded programs should be restructured to preferentially fund models of healthcare that are holistic and family-centered, such as those that promote and support breastfeeding as a health promoting, life sustaining traditional practice, and the midwifery model of care. Evidence-based outcomes indicate the midwives are the primary MCH providers in countries with the lowest infant mortality rates in the world; midwives provide safe and satisfying care at a fraction of the cost of physician-based medical models.

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A Model That Works!
Healthy Start Projects Serving
American Indians and Native Hawaiians

"Interventions should be holistic and integrate the best of Western medicine and traditional Native medicine."
Healthy Start Indigenous Peoples Summit
Healthy Start is a federal initiative inaugurated by Congress in 1991 and is administered by HRSA’s Maternal and Child Health Bureau (MCHB) whose purpose is to address the alarmingly high rate of infant mortality in the United States, particularly for minority populations. Healthy Start provides funds for maternal and child health (MCH) programs to at-risk communities and populations. These communities have infant mortality rates that are at least one and a half times the national infant mortality rate. Nationwide, there are over ninety Healthy Start projects; six Healthy Start (HS) projects specifically target Native people. Healthy Start’s vision is to create the best community-based, community-driven approach to infant mortality reduction. The primary charge of all Healthy Start projects is to ensure that at-risk pregnant women and their infants receive early and regular access to perinatal services during pregnancy and a continuum of care until two years post-birth. Healthy Start’s key strategies are case management and interventions that are specifically tailored to each distinct community.

Although there have been some improvements in the past decade, in some areas of the U.S. Native babies die at a rate that is two to three times higher than the rate for White American babies. In addition, for Natives babies the incidence of Sudden Infant Death Syndrome (SIDS) is as much as three times the U.S. average rate. And while the reasons for these confounding disparities are complex, discrimination in service delivery plays a significant part, as well as lack of maternity care models that fully engage Native consumers.

In order to better understand racial disparities, unique healthcare needs, and cultural diversity among discreet populations of indigenous people, in February 2003 the Healthy Start Native Peoples Council (HSNPC)—a consortium of Healthy Start projects serving indigenous families nationwide—convened a conference entitled the “Healthy Start Indigenous Peoples Summit.” The summit agenda focused on issues that impact maternal and child health (MCH) and participants collaborated to create recommendations for organizations and agencies working with Native people. Overall, summit participants stated that while current perinatal systems are inadequately meeting the needs of American Indian and Native Hawaiian women, infants and families in fundamental ways, Healthy Start models are successful in identifying complex problems, demonstrating best practices, and providing innovative programs in Native communities. In many cases, Healthy Start projects have succeeded in increasing use of first trimester prenatal care, reducing the incidence of risk behaviors, and lowering the infant mortality rate.

Participants at the summit pondered the reasons for Healthy Start’s success. In analyzing data from conference focus groups, four key characteristics emerged as distinctly responsible for the success of the Healthy Start projects serving Native people. These characteristics are: 1) importance placed on cultural competency in healthcare; 2)
honoring the centrality of women’s health in family health; 3) embracing the community-oriented nature of the Healthy Start projects; and 4) a willingness to address issues related to racism.

Culturally Competent Services, Providers and Materials
Cultural competency includes cultural awareness, cultural knowledge, cultural skills, and cultural encounters. These components must be systematically incorporated at each level in perinatal systems, including policy making, administration, service delivery, and in educational materials. Healthy Start projects that serve Native people are raising awareness of the need for cultural competence in the provision of services and are working to educate providers about what culturally competency “looks like” in the provision of healthcare to Native recipients. Professionals need to recognize that it is not only what information or services they teach or provide that matters, but how they are given and communicated to the client.

For example, Healthy Start offers cultural programs for men in order to deal with anger issues and to reclaim their traditional roles within their tribes and clans. Healthy Start makes referrals to cultural and spiritual healers to assist women and families in becoming more “spiritually balanced” in their lives (which is an important concept in Native cultures.) Healthy Start supports access to alcohol and drug treatment programs and compassionate healthcare for women with addiction problems, rather than targeting women for criminal investigation. Initiating early and supportive interventions can sometimes prevent traumatic removal of children from their homes. Healthy Start provides tools to assist people in taking responsibility for their own health and their family’s health, such as culturally-based smoking cessation programs. Healthy Start supports health education and prevention projects such as the Pink Shawls Project for breast health awareness. Healthy Start is teaching service providers about Native culture, health-seeking behaviors, and traditional values and beliefs by supplying them with culture-based teaching materials such as the “Back to Sleep, Back to Tradition” and the “Face Up to Wake Up” educational resources regarding safe sleep practices, which blend traditional wisdom with Western science. Healthy Start addresses the problem of obesity sweeping Native communities by educating about good nutrition and exercise and the benefits of returning to the types of traditional diets and activities that kept Native people nourished and healthy before European influence. Healthy Start provides support for the time-honored practice of breastfeeding within Native cultures. Healthy Start staff (many of whom are trained lactation Consultants) teach that breast milk is not only the best food for babies and most convenient way to feed babies, but also breastfeeding provides numerous other benefits to mothers, babies and families. Returning to breastfeeding is returning to cultural ways of nourishing children in Native communities.

In both research and clinical arenas, there is a general recognition of the important role culture plays in health. When primary health care services are culturally competent there are more favorable outcomes and greater satisfaction for the individuals receiving care. Healthy Start Summit participants emphasized that culturally appropriate healthcare services and providers are critical to fully engage Native people and ensure utilization of existing maternal and child healthcare systems.
**Women’s Health Is Central to Family Health**

Perinatal health exists within the context of a woman’s overall health status and environment. Most maternal and child health programs rely exclusively on the provision of clinical services and inadequate attention is paid to conditions of everyday life such as income, housing, diet, education, employment, transportation, social support, safety, and environment. These conditions are crucial determinants of health.

There is a new and long overdue focus emerging in health policy and program design that rightfully acknowledges the role that woman play in maintaining and promoting healthy behaviors and lifestyles in their families and communities throughout their lives. However, this perspective is a very ancient and well-established concept in most Native cultures. As stated at the Healthy Start Indigenous Peoples Summit, “We believe that women are sacred because they give life and sustain life, like the Earth, and we believe that we as a people and a society have an obligation to support, honor, and respect women’s needs and health issues.”

Native people want access to maternal and child healthcare that supports their traditional beliefs and practices while offering the best of conventional Western medicine. This approach to healthcare has specific characteristics: it does not frame women’s healthcare solely within the context of reproductive function; it focuses attention on the basic health needs of women throughout the life span; it is holistic and multi-dimensional and includes health promotion and disease prevention components; it acknowledges the social, cultural, economic and political context in which health occurs; and it includes the health of the entire family system as defined by each woman. Healthy Start models are demonstrating best practices in providing innovative, holistic, and woman-centered care in Native communities.

**Community-oriented Strategies for Infant Mortality Reduction**

Programs that are fashioned to serve Native people should be structured so that Native people are making decisions about them. Programs designs, no matter how visionary and well intentioned, can be myopic and reactive if they are not inspired and informed by the target audience. Native people need to be full partners in program planning and often in the existing healthcare system Native people are not invited to the planning table.

Additionally, maternal and child health policies and programs should prioritize utilization of Native staff to serve within Native projects and strategize ways to increase career ladder opportunities for Native people to achieve these goals. The “face” of culturally competent programs in Native communities needs to include Natives faces.

The community-based, community-driven structure of Healthy Start is a positive approach. The Healthy Start model demonstrates ways to ensure comprehensive maternity care to Native communities; to capitalize upon the strengths and cultural resources that already exist within Native populations; to provide a blending of cultural and medical resources that result in the kind of holistic approach preferred by Native people; and to incorporate community members as advocates and health educators in
raising awareness about the problems of infant mortality, promoting healthy behaviors, and encouraging mothers to receive early and regular prenatal care. Healthy Start is a work in progress that is developing best practices for enhancing and improving healthcare provided to Native families and communities.

Confronting Racism

Native people (as reported by summit participants from all six Healthy Start sites) experience discrimination and racism within perinatal healthcare systems, which impacts their willingness to utilize services and trust providers, and increases their stress levels. There are well-documented biologic consequences of social stress in pregnancy including: changes in maternal hormone levels and placental functioning; preterm birth; and low birth weight. Racism produces anxiety and stress as well as impacts health-seeking behaviors, impacts mental health, and increases use of alcohol, drugs, tobacco and violence among Native people.

Racism can occur on three levels: 1) institutional racism affects access to goods, services and opportunities; 2) personally-mediated racism affects assumptions about a person and results in stereotyping and discrimination; and 3) internalized racism affects acceptance of negative messages about one’s own abilities and intrinsic worth. In order to confront the profound affects that racism has historically played and continues to play in health disparities, health policy, and the delivery of healthcare, we must advocate for a social justice agenda on all levels: within healthcare systems, in provider-client relationships, and within individual consciousness. In many ways, Healthy Start is a model for a social justice agenda. Participants of the Healthy Start Native Peoples Council have identified ways in which their respective Healthy Start projects are exposing racism and the central role it plays in perpetuating racial health disparities. But they have also identified strategies for promoting anti-racist policies and practices in caring for mothers, infants and their families. Healthy Start projects are creating innovative strategies to celebrate the gifts inherent in cultural diversity and increasing Native peoples’ pride in their unique heritages.

Conclusion

Through Healthy Start we have opened new doors in our understanding of those circumstances and factors that have created racial disparities in health status for Native people and are gathering data about what good quality, satisfying, culturally competent service looks like to Native people. We are closing the gaps in unequal treatment by striving to provide and advocating for equal access to comprehensive, culturally competent, holistic maternal and child healthcare services for all.

The Healthy Start Native Peoples Council recommends the following action steps:

1. Congress should enact legislation to make Healthy Start a permanent federally funded program (similar to Head Start and WIC) in order to establish it as an essential community-based healthcare service for at-risk American mothers and infants.
2. State public health departments, MCH agencies, and educational institutions should develop official policies and earmark funding to create opportunities for recruitment, education and career development to increase the number of Native professional staff.

3. Maternal and child health programs that use federal and state dollars should be culturally competent. To ensure this level of competency, federal agencies should give preferential points to MCH grant proposals that can validate that they serve Native communities, have Native advisory Boards, are managed by Native leadership, have Native staff, and have MCH programs that utilize cultural interventions and health-promoting strategies geared towards Native clientele.

4. Maternal and child health programs that use federal and state dollars should address women’s comprehensive needs across the lifespan and not be framed solely within the context of reproductive function. MCH programs should reflect the social, economic, cultural and political contexts in which maternal and child health occur by expanding MCH services to meet the needs of target populations.

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Partnership in Progress: Strengthening the Relationship Between the Federal Government and Indigenous Communities in Maternal and Child Health Efforts

"The healthcare system’s response should be congruent with the promises of the treaties between Native people and the U.S. government to provide for the health, education, and welfare of indigenous people in exchange for the lands that were given up."
Healthy Start Indigenous Peoples Summit
Partnership in Progress: Strengthening the Relationship Between the Federal Government and Indigenous Communities in Maternal and Child Health Efforts

Closing the health disparity gaps between minority and majority populations is a stated priority for the U.S. Department of Health and Human Services. American Indian and Native Hawaiian populations experience some of the highest health disparities among all population groups in the U.S. starting at birth and continuing across the lifespan. Native leaders are calling for greater attention and responsiveness from federal partners. Numerous Presidential Executive Orders and U.S. Department of Health and Human Services official policies and initiatives call for enhancement of the government-to-government relationship between tribes, tribal organizations, and federal agencies. Congress has repeatedly recognized the special responsibilities the federal government has to promote and protect the well-being of Native Hawaiians. The U.S. Commission on Civil Rights, an independent bipartisan agency established by Congress in 1957 recently submitted a comprehensive report to Congress and the President entitled “Broken Promises: Evaluating the American Indian Health Care System”. This extensive report details disparities, socio-cultural, structural and funding barriers and over 100 proposed legislative changes and recommendations. Despite these clear policies and calls for improvement, disparities persist. To make progress in eliminating health disparities within Native populations, these policies must be acted upon through a strengthened partnership between Native groups and federal agencies and departments.

Critical Needs and Missed Opportunities

Maternal and child health disparities between indigenous and other population groups are high, particularly in the area of infant mortality, Sudden Infant Death Syndrome (SIDS) and postneonatal deaths. On the Big Island of Hawai‘i, for example, while Native Hawaiians account for 28% of the total population, and 45% of all live births, they experience 60% of all infant deaths. American Indians in some areas of the U.S. have infant mortality rates which are two to three times the rate among White Americans; in Northern areas of the U.S. the American Indian SIDS mortality rate is as much as three times the national average.

Some indigenous communities are among the poorest, most destitute communities in the country. Several large Indian reservations are located within the most impoverished counties in the United States, with unemployment rates over 50%. Of all ethnic groups in Hawai‘i, Native Hawaiians have the worst health status and the highest poverty rates. Native Hawaiians and American Indians, as a whole, are often referred to as having the most compromised health status of all ethnic and racial groups in the United States.

Of equal significance are the substantial strengths, resources and resiliency which exist in Native communities, and have persisted despite systematic attempts at cultural
annihilation. Among these strengths are a strong sense of intergenerational connection and responsibility, reverence and respect for Elders and their teachings, traditional beliefs which uphold the sacredness of women and children, and traditional practices which promote good nutrition, physical activity and emotional well-being. Programs which acknowledge and capitalize on these traditional resources, when appropriately directed and supported with adequate funding, have the most chance for both acceptability in the communities and for success. To not fully incorporate and utilize these resources is to miss a key opportunity to make real progress in improving indigenous maternal and child health. At present, the budgetary and programmatic guidelines of many federally sponsored programs limit the full utilization of cultural and traditional resources. Potential cultural, spiritual and ceremonial program components generally lack a scientific evidence base in the current literature, and thus are rarely accepted as legitimate components of interventions or program costs.

A Unique Relationship and Distinct Responsibility

American Indians and Native Hawaiians are the indigenous peoples of the United States. These populations have a unique relationship with the federal government because of their special history of being dispossessed of their ancestral lands and associated social systems. Geographic displacement and implementation of overt policies aimed at eliminating their social organization, language and culture had a profound effect on the Native peoples of this country. The multi-generational trauma that has resulted from these past official policies is a key underlying factor behind the poor health status of modern indigenous communities. The U.S. government has a special government-to-government relationship with tribes and a distinct and direct responsibility to provide for the health care of the indigenous people of this country. This special government-to-government relationship is affirmed in numerous treaties, statutes, and executive orders, as well as legal, moral and ethical principles. Likewise, federal legislation affirms the special responsibilities and legal obligations of the federal government to the indigenous people of Hawai‘i, most specifically through the 1988 Native Hawaiian Health Care Act, and provisions within the 1959 act which admitted the State of Hawai‘i into the Union.

The Indian Health Service (IHS) is the primary agency designated to meet the health care needs of documented members of federally recognized Indian tribes. However, at present funding levels, the IHS is only funded at approximately 35% of the level of need. In 2001, IHS per capita spending on personal health services for IHS users was $1,776. This can be compared to per capita spending on health coverage for federal IHS employees of $2,980 in 1999. for federal employees health plan costs to IHS. In other words, the federal government spends 68% more per capita on health coverage for IHS employees than it spends on health care services for its target population. Because of this spending shortfall, access to and full participation in the full range of programs and services funded by the U.S. Department of Health and Human Services and other entities is crucial for addressing the high level of need in Native populations.

In the case of Native Hawaiians, proposed fiscal year 2006 funding for the Native Hawaiian Health Care Act is about $12 million for 400,000 Native Hawaiian people – or
$30 per person. The Native Hawaiian health care system is clearly under-funded. A newly formed collaborative, or “Hui” of Native Hawaiian Health Centers recently issued a position report stating concern over recent changes in federal management of the Native Hawaiian Health Care Improvement Act. These concerns include a lack of respect and a lack of incorporation of the community-based governance process developed over many years in Hawaiian communities, as well as concerns over how newly appropriated funds are distributed.


All Native peoples and Native organizations face the challenge of “walking in two worlds.” This requires incorporating and honoring both the personal and social protocols of their indigenous culture and world view, while at the same time trying to negotiate and interact in a successful way with the larger Non-Native society. This places a unique stress on indigenous people, and indigenous organizations, and presents barriers to full participation in federal programs.

The unique characteristics of indigenous cultures and indigenous community organizations affect their members’ access to and full participation in federal MCH programs. Often despite language in official documents which affirm the eligibility of Native and tribal organizations to participate in federal initiatives, policies and programs are not structured or administered in such a way as to facilitate participation by indigenous groups or to be relevant in a Native community setting. Currently, tribes and tribal organizations are eligible to apply to 125 out of 315 grant programs within the U.S. Department of Health and Human Services, however at present, only 85 out of the 125 are being accessed. Many federal resources in health care are dispersed through competitive grant processes. Consequently, funding awards often reflect grant writing ability and organizational infrastructure as much or more than need within the population. Many federal programs require minimum population numbers within a specific geographic target area to be eligible for participation. The geographic dispersal of many Native populations often makes them ineligible to participate. Additionally, federal programs place a high value on implementing standardized, evidence-based approaches, and academic rigor. This orientation puts Native communities at a further disadvantage, despite their very high level of need. Most program models that have been standardized and have a strong evidence base are derived from studies conducted in Non-Native populations. There is very little published research on effective interventions specific to Native communities, yet there is much untapped wisdom and potential at the community level.

The conventional public health bureaucracy places a high value on program accountability provided through rigorous documentation and evaluation, fueled by the Government Performance and Results Act of 1993. The level of reporting and documentation that is often now required by federal programs takes a significant proportion of program resources to generate, and diverts significant efforts and funds away from service provision. Many indigenous groups and organizations have limited
staff resources if they have access at all to advanced professional skills in grant writing, database development, and statistics. The amount of data collection and reporting that is more and more frequently being required is overly burdensome to programs. It is also felt that while the kinds of information that are required for reporting reflect priorities within the general U.S. population, they do not always reflect pertinent issues in Native health nor succeed at capturing the benefit or achievement of programs. In contrast to the federal emphasis on demonstrating cost-benefit, and documenting quantitative outcomes, indigenous populations place primary importance on provision of services which are personal, and consistent with cultural and social values of the community. The primary focus of accountability is acceptance within the community. Indigenous organizations have been broadly characterized as “low structure, high caring”. The most successful programs and services, both in terms of outcomes and community acceptance, feature either Native providers, or Non-Native providers who have made the lengthy time investment needed to gain the community’s trust and to develop the skills necessary to consistency engage clients. There is a severe scarcity of both. Indigenous groups located in isolated geographical areas can have great difficulty in recruiting well trained, appropriate providers and other staff to implement programs. Many programs designed to serve Native populations rely heavily on Non-Native providers and administrators, and experience high turn over rates, making the establishment of highly effective and culturally relevant services all the more challenging.

Numerous logistical and operational requirements that come with federal funding are based on Non-Native values and hamper the effectiveness of programs that intend to serve Natives. For example, budget regulations often prohibit the use of funds for incentives, food, and ceremonial supplies which are essential to engaging communities who place a high value on traditional cultural practice. Because many Native populations are geographically dispersed, and often reside in rural and isolated areas of the country, outreach involves expensive and time consuming travel and communications. Funds are often inadequate.

Indigenous groups are hampered by a lack of visibility, and recognition of their health issues. Much of this “invisibility” is attributable to a lack of data. Numerous powerful health data compilation and analyses systems are in place which are federally supported and managed, and publicly available. These include databases managed by the National Center for Health Statistics (NCHS), the U.S. Census and Centers for Disease Control and Prevention (CDC). Published racial comparison data most often either excludes data for Native populations or lumps statistics for American Indians in with a wide variety of other groups into the racial category of “Other”, often a synonym for “too small to worry about”. Data for Native Hawaiians is often reported under the category “Asian and Pacific Islanders”. The socio-economic and health status of the other larger sub-groups in this category (namely Japanese and Chinese) effectively disguises the health disparities of Native Hawaiians when all are reported under one combined category, as is standard practice. Existing vital records and public health surveillance systems do not adequately or accurately provide basic demographic and health outcome statistics for indigenous populations. Federal leadership is needed in promoting and requiring improved standards
at the State and local levels to more accurately include Native populations in the variety of data gathering and analyses systems in place.

Finally, the Native view of health includes the health of family and community members as directly connected to one’s own health. Native people and Native communities view health in a holistic, integrated way, with physical, spiritual, and emotional health as being inextricably connected. Categorical funding which establishes programs in response to specific diseases and strict age categories is in sharp contrast to this indigenous orientation. Intervention models and required components of federal programs tend to reflect a “one size fits all” mentality, and although Native representatives may often be invited to provide input into federal planning and review processes, it has been experienced in many cases, that decisions have been predetermined and their input is ignored.

**Responding to the Challenges: Strengthening the Relationship**

First and foremost, when federal agencies develop policy and program guidelines, representatives and leaders from Native communities should be involved as full partners and have significant involvement in key decision making. Too often programs and agencies establish “token” representation on advisory committees that have little or no real input on final policies and decisions. Native people and people who understand the “walking in two worlds” context in which indigenous programs operate need to be involved in key policy and programmatic decision making. Federal agencies should dialogue with indigenous groups about what kinds of information collection is feasible and meaningful; and work together to create strategies that will make it possible for indigenous groups to comply with federal requirements. Federal programs should recognize that “one size does not fit all” in programs for underserved populations and that cultural awareness and knowledge is necessary when designing, developing and implementing MCH programs for Native people. Programs with a comprehensive, holistic and intergenerational approach are needed. Health care which is organized by body system or disease group does not correspond to how Native people conceptualize their health or capacity to heal and maintain health. Federal funding should be made available for programs which feature comprehensive and integrated interventions.

**The Healthy Start Native Peoples Council recommends the following action steps:**

1. Congress must fund the Native Hawaiian Health Care Improvement Act, Native Hawaiian Education Act, and the Indian Health Service to full capacity, and work to fulfill treaty obligations regarding healthcare provision to America’s indigenous populations. The specific recommendations to Congress, the Indian Health Service, the Centers for Medicare & Medicaid Services, and the Department of Health and Human Services issued in 2004 by the U.S. Commission on Civil Rights should be fully implemented. At the State level, Title V Maternal and Child Health Block grants should include health indicators and program funding aimed at addressing disparities within Native populations.
2. The U.S. Department of Health and Human Services (DHHS) must improve its partnerships with Native populations by ensuring that its Tribal Consultation policy is fully adhered to by all departments. All DHHS departments should ensure that adequate American Indian and Native Hawaiian representation is involved at key policy and decision-making levels especially when developing new grant opportunities and setting eligibility and program component requirements.

3. Federal and State funding should be made available for programs that feature comprehensive and integrative healthcare interventions, and Native-specific traditional healing and health promoting practices, such as breastfeeding support, must be acknowledged and included as allowable program costs.

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Endorsing Maternal and Child Health Data Collection and Research Agendas That Include American Indians and Native Hawaiians

“It is impossible to address racial and ethnic disparities in health status without adequate data. Data provides knowledge, and knowledge provides power to construct effective interventions.”

Thomas E. Perez
The Civil Rights Dimension of Racial and Ethnic Disparities in Health Status
Mounting evidence suggests that preventable disparities between Native and White populations in maternal and infant status persist. Nonetheless, reliable and widespread data are extremely limited with regards to Native populations. Native people are the least studied sector of the population, perhaps because they represent the most diverse populations in the United States. Very few studies have examined the quality of healthcare for Native Americans, Alaskans Natives and Native Hawaiians. Subgroups of these populations are rarely explicitly studied, in part due to the small sample size of these populations, which makes analysis more challenging.

Gathering health data and conducting research is typically done within academic, governmental or corporate structures, each of which is in a position to staff projects and generate or receive funding for such endeavors. Many Native-based healthcare programs—most of which collect program data relevant to disparities and racial and ethnic determinants of health—typically have serious limitations in staffing, technology and funding needed to fully utilize these data. Available staff and funds are primarily dedicated to programmatic efforts.

Indigenous groups are hampered by a lack of visibility, and recognition of their health issues. Much of this “invisibility” is attributable to a lack of data. Racial comparison data very often lumps statistics for American Indians in with a wide variety of other groups into the racial category of “Other”, often a synonym for “too small to worry about”. Data for Native Hawaiians is often reported under the category “Asian and Pacific Islanders”. The socio-economic and health status of the other larger sub-groups in this category (namely Japanese and Chinese) effectively disguises the health disparities of Native Hawaiians when all are reported under one combined category, as is standard practice. Existing vital records and public health surveillance systems do not adequately or accurately provide basic demographic and health outcome statistics for indigenous populations.

**Culture-specific Data Collection for Native Populations**

A significant and limiting factor in contemporary research on racial and ethnic disparities “is the failure to analyze differences beyond comparisons of African-Americans and White patients.”

The United States Congress commissioned a recent study by the Institute of Medicine on racial and ethnic disparities in healthcare. The IOM report concluded that little or no data were available for Native populations. However, in the studies reviewed by the IOM, race and ethnicity typically emerged as significant predictors of quality of care received and health status for all minority populations.
Reliable and wide-spread data on Native populations are extremely limited with regards to such measures as:

- causes of preventable disparities in maternal and child health;
- useful and effective interventions to improve health status and decrease disparities and barriers to care;
- how the perception of discrimination, quality of care, and “trust” issues affect the degree to which Native women effectively utilize the perinatal healthcare system;
- the proportion of Native mothers that require an intensive number of prenatal care visits or use tertiary care units;
- preferences in utilization of providers and facilities among Native women and their partners;
- and the role culture plays in perinatal outcomes.

For over a decade, quantitative and qualitative data have been gathered at Healthy Start sites serving Native populations that illustrate health problems Native people and communities face, as well as problems within perinatal systems serving these populations. Data gathered from Healthy Start staff and clients, case management documents, focus groups, interviews and conferences suggest that American Indians and Native Hawaiians, generally speaking, grapple with the following concerns:

- difficulty in accessing healthcare;
- fewer choices of where to receive care;
- lower quality of health services;
- fewer care providers who are members of their own cultures or who are culturally competent in providing services;
- discrimination based on race or ethnicity;
- significant impact of risk behaviors on Native communities;
- chronic and acute health problems;
- and poorer health outcomes.3

Data Collection and Reporting Standards Which Hamper Accuracy

Native people are often misreported on vital records as White or Hispanic. Frequently members of the Native population have multiple races in their family history; without the option of reporting more than one race, many Native people are not counted. For birth records, race of the infant is determined by race of the mother, eliminating infants with Native fathers from counts. This issue skews the calculation of infant mortality rates as well. Often race is recorded based on appearance, rather than on self report. For American Indians, tribal affiliation, is not universally recorded on birth or death certificates. This makes tracking data specific to these populations, especially sub-groups, and calculating infant mortality and morbidity inconsistent and inaccurate, thus blurring statistical evidence about infant and maternal mortality and morbidity and their impact on Native communities.
Conclusion
Racial and ethnic disparities in healthcare exist; they are consistent and extensive; they exist for all minority populations including American Indians and Native Hawaiians; and they are associated with poorer health outcomes. While we acknowledge a lack of full understanding about the sources and causes of these disparities, further research has the potential to enhance our understanding, improve the quality of care and health status for special populations, and ameliorate the health of this nation’s people and its communities.

Discrimination continues to exist when Native people are not brought to the table as full partners in data collection, program planning and policy development for their communities. Maternal and child health program planners and administrators may not fully understand the issues facing Native communities relative to maternal and child health (MCH) status. Unless key players are aware of the racial disparities at the local, regional and national levels, quality services and providers may not reach Native populations. In the United States, we have the most advanced and complex healthcare system and health information systems available, but our most vulnerable “first nation people” are not adequately represented in these systems, and there has been little emphasis placed on making improvements. Without a better understanding of the health issues facing Native populations, decreased access to a continuum of good quality care will be the norm for American Indians and Native Hawaiians, and disparities and poor MCH health outcomes will persist. These disparities and inequalities are not acceptable.

The Healthy Start Native Peoples Council recommends the following action steps:

1. Federal agencies including the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Department of Health and Human Services (DHHS) should encourage collaboration with academic partnerships by requiring that all federally funded research projects involving Native populations include substantial roles for Native people as full partners in the research process, and provide training and support for this involvement as appropriate. Training programs and leadership opportunities for Native people engaged in health research should be expanded.

2. Federal agencies including the National Center for Health Statistics and the CDC, as well as State vital records and statistical bureaus should review standards for reporting of race. Changes at the State and local levels should be required that will allow for more accurate collection and compilation of health data on American Indian and Native Hawaiian populations, including collecting data on tribal affiliation. Additionally, tribal health authorities should be given the same access that local county health department have to birth and death certificate data and files for their service population. Whenever possible, appropriate statistical methods should be used to contend with small numbers in order to yield Native specific data, rather than reporting under the racial category “Other”.

3. The CDC, NIH and U.S. DHHS should expand research opportunities and design project parameters so that small indigenous groups with limited resources in
staffing, technology and funding can participate. These opportunities should include support for the higher costs and greater complexity involved in conducting research in indigenous communities that encompass vast and remote geographical areas.

References

1 Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, Institute of Medicine, 2002.
2 Ibid.

Healthy Start Native Peoples Council: 
A Consortium of Healthy Start Projects Serving Indigenous Families
Aberdeen Area Tribal Chairmen’s Health Board: Northern Plains Healthy Start
City of Minneapolis: Twin Cities Healthy Start
Great Lakes Inter-Tribal Council: Honoring Our Children Project
Inter-Tribal Council of Michigan: Maajtaag Mnobmaadzid (A Start of a Healthy Life)
State of Hawai’i Department of Health: Malama A Ho’opili Pono Healthy Start Project
University of North Carolina at Pembroke: Healthy Start CORPS

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Healthy Start Project Sites Serving Native People

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