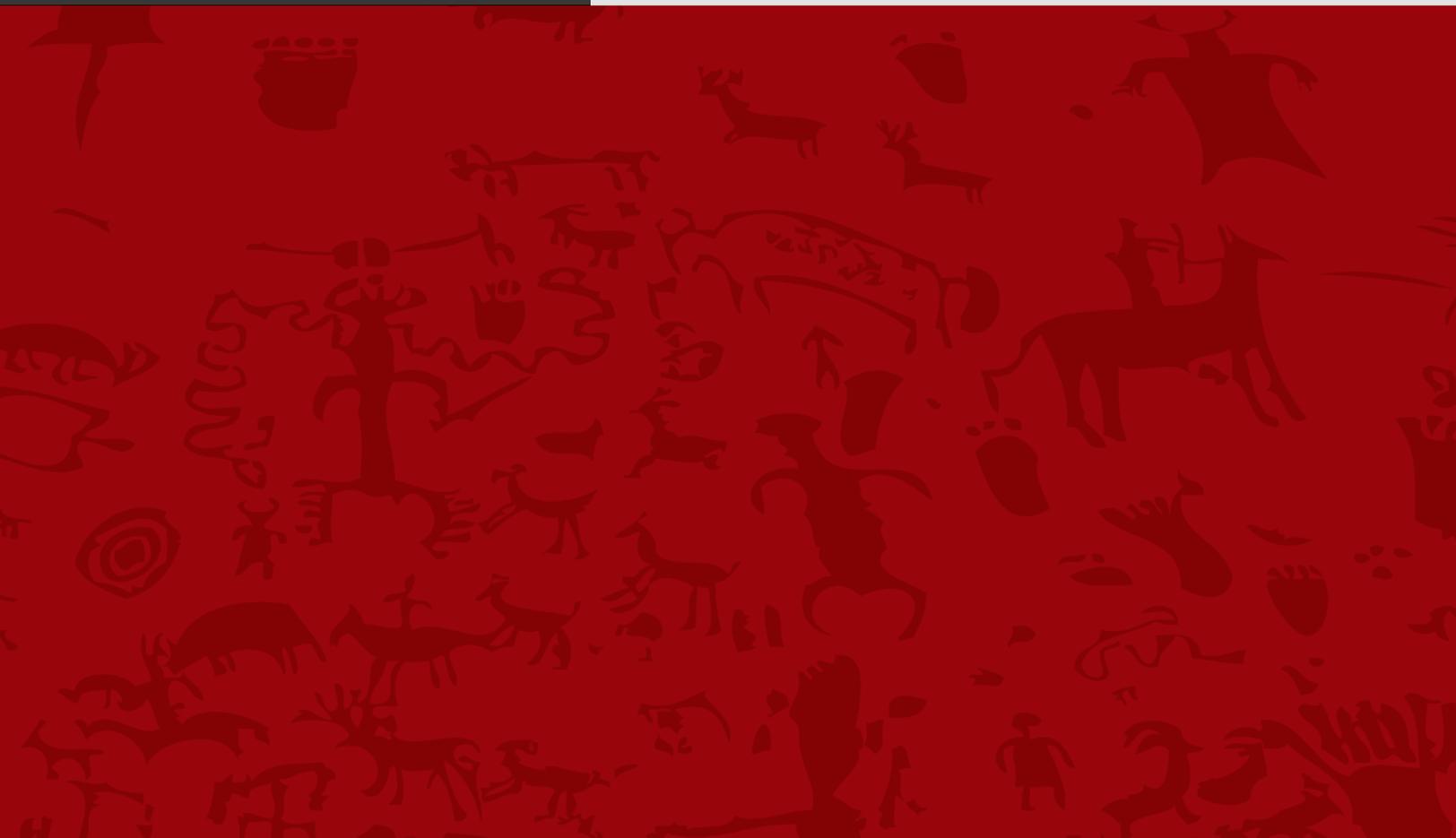




**Looking to the Past to Improve the Future:
Designing a Campaign to Address Infant
Mortality among American Indians and Alaska
Natives**

January 2011





The mission of the Urban Indian Health Institute is to support the health and well-being of Urban Indian communities through information, scientific inquiry and technology.

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A Division of the Seattle Indian Health Board

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I. Introduction

American Indians and Alaska Natives (AI/AN) experience some of the highest disparities in infant mortality across the country. In some areas, infant mortality rates for AI/AN are four times higher than among whites. The national rate for AI/AN, while higher than the general population, does not reflect this variability and the true severity of the issue in some communities. Causes of death and risk factors for infant mortality within AI/AN include Sudden Infant Death Syndrome (SIDS), infections, injury, limited access to culturally appropriate health care resources, and other socioeconomic, historical and political factors. Despite high rates of infant mortality, there is little evidence of effectiveness of interventions for AI/AN. Current approaches to infant mortality awareness and prevention in the general population often do not reach AI/AN and may not be entirely appropriate for AI/AN; with a focus on different risk factors and outcomes, access to resources inaccessible for AI/AN, and lacking adequate consideration of relevant cultural factors.

There are three aims for this report, which will be used towards the overall goal of informing the development of a communication campaign to increase awareness of infant mortality among AI/AN. These aims are: 1) outline the burden of infant mortality and associated risk factors and barriers to improvement among AI/AN nationwide, 2) provide an overview of the health communication campaigns that have been directed to this population including the range of topic areas and methods for reaching AI/AN and 3) discuss select previous and current efforts on infant mortality prevention among AI/AN.



II. The Need

Infant Mortality Rates

In 2006, the infant mortality rate among AI/AN nationwide was 50% higher than in non-Hispanic (NH) –whites (8.3 and 5.6 per 1,000 births, respectively) (Matthews, 2010). State-specific data on infant mortality is limited for AI/AN due to relatively small population numbers; available data show a range of 6.3 to 12.3 per 1,000 live births. Infant mortality rates among AI/AN in urban areas (8.1 per 1,000 live births) are also higher than rates for all races residing in the same urban areas (6.0 per 1,000 live births) (Centers for Disease Control and Prevention (CDC), 2001-2005; UIHI, 2009). Rates for urban-residing AI/AN differed based on area, ranging from 3.6 to 14.3 per 1,000 live births.



When infant mortality is subcategorized into neonatal mortality (deaths per live births less than 28 completed days after birth) and post-neonatal mortality (deaths between 28 days and 364 days after birth) neonatal mortality rates among nationwide AI/AN are higher than NH-whites (4.3 and 3.6 per 1,000 live births respectively), but marked disparities are seen in the post-neonatal period with mortality rates for AI/AN more than twice that for NH-whites (4.3 and 1.9 per 1,000 live births respectively) (Matthews, 2010). In a recent study by Alexander et al, after adjustment for maternal risk factors, rates of post-neonatal mortality among AI/AN remained significantly higher than whites (Alexander, 2008).

Neonatal deaths are usually linked to congenital anomalies and high-risk births, which include low birth weight (LBW), preterm birth, and large for gestational age (birth weight >90th percentile of birth weight for gestational age) births. Even after adjustment for maternal risk factors, AI/AN have higher risks than whites of low birth weight (5.8% and 4.9% respectively) and preterm birth (11% and 8.3% respectively) (Alexander, 2008).

Looking further at the clinical conditions linked to rates of neonatal mortality, high macrosomia rates (birth weight >4000g) of 16–31% have been reported among several North American Native groups, including First Nations in Canada (Rodrigues, 2000). Additionally in 2006, rates of macrosomia were higher among AI/AN compared to whites (9.8% and 8.7% of live births >4000g, respectively) and AI/AN had a higher percentage of infant deaths among birth weights >4000g compared to whites (4.8% and 2.2% infant deaths >4000g, respectively). The cause for the higher birth weights among AI/AN may be due in part to the higher prevalence of maternal obesity and diabetic risk in this population, but there may also be racial/ethnic differences in the effects of maternal diabetes on birth weight (Rodrigues, 2000).

Rates of post-neonatal death among AI/AN are also likely impacted by higher birth weight/gestational age specific mortality rates seen in this group. In data from 1995-2001, the mortality rate among mothers at 42+ weeks and infants 4250g+ among AI/AN was 3.0 compared to 1.5 per 1,000 live births among whites (Alexander, 2008). In data from 2006 on gestational age independent from birth weight, infant mortality rates were higher among AI/AN mothers when compared with NH-white mothers at both 34–36 weeks of gestation (9.7 and 6.6 per 1,000 live births) and 37–41 weeks of gestation, considered “term” (4.9 and 2.2 per 1,000 live births) (Matthews, 2010).

II. The Need

Causes of death

Examination of cause-specific death rates show that AI/AN have significantly higher rates than NH-whites for three of the four leading causes of infant mortality, including: congenital anomalies, SIDS, and unintentional injuries. Cause-specific death rates among AI are still significantly increased above whites for perinatal conditions, SIDS, injury and infections after adjustment for maternal risk factors (Alexander, 2008).



The SIDS rate among AI/AN is 115% higher than for NH-whites (119.4 and 55.6 per 100,000 live births respectively), with an increase from 2005 to 2006 among AI/AN. Depending on the region, the rate of SIDS is 2 to 4 times greater than for the U.S. population (U.S. Department of Health and Human Services (U.S. DHHS), 2002). Among AI/AN in urban areas, the SIDS rate is 80.0 compared to 30.0 per 100,000 live births among all races (CDC, 1996-2005).

Historically, AI/AN have the highest risk for unintentional injury mortality compared to other races (Tomashek, 2006; Jain, 2001; Overpeck, 1999). For AI/AN, infant mortality rates from unintentional injuries are triple those for NH-whites (Matthews, 2010). One study found that AI continued to have an increased risk for both homicide and fatal unintentional injuries even after adjusting for multiple socio-demographic risk factors (adjusted odds ratio = 1.6 and 2.1, respectively) (Jain, 2001). Authors also note that results may be conservative estimates of the incidence of injury related deaths based on known misclassification of AI/AN in vital records (Stehr-Green, 2002; Epstein, 1997).

Respiratory distress related to influenza or pneumonia is also a cause of increased infant mortality rates among AI/AN with risk increasing as birth weight decreases in general (Singleton, 2009). In a recent study, infant deaths from lower respiratory tract infections (LRTI) were highest among AI/AN compared with white infants, and disparities persisted among infants with birth weight at ≥ 2500 g and those who did receive early prenatal care (Singleton, 2009).

Risk factors for poor birth outcomes

When looking at risk factors for poor birth outcomes among live births, American Indian and Alaska Native mothers are more likely to be unmarried, less than 18 years old, to have pregnancy induced hypertension, diabetes, and to smoke or drink alcohol compared to whites (Alexander, 2008).

Obesity, gestational diabetes, and types 1 and 2 diabetes, which are prevalent among American Indian and Alaska Native women, are independently associated with an increased risk of large for gestational age births, preterm births, birth injury, and macrosomia (Reece, 2009; Sayers, 2009; Ben-Haroush, 2009). Further, there is a threefold to fourfold increase in major congenital anomalies occurring in women with these conditions and even higher absolute and relative risks for particular malformations, such as neural tube defects.

Disparities in risk factors among AI/AN in urban areas compared to the general population in the same areas are similar and include the rate of births to: teenage mothers (6.2% and 3.1%, respectively), unmarried women (63.6% and 35.3%, respectively), women who received late to no prenatal care (8.2% and 3.9%, respectively), and women who consumed alcohol (3.2% and 0.9%, respectively) or smoked while pregnant (15.0% and 8.0%, respectively). Additionally, in examinations of national survey data, urban AI/AN have higher rates of teen pregnancies, unintended pregnancies and mistimed pregnancies than NH-whites (Rutman, 2008; UIHI, 2010).

II. The Need

Barriers to care

Regarding access to prenatal care, American Indian and Alaska Native women face numerous barriers which may include conflict between traditional beliefs and practices and the Western model of care, and provider characteristics such as disrespect, hostility, and paternalism (Long, 1998). Perceived racial prejudices in healthcare delivery have also been found to negatively affect women's protective health behaviors (Thorburn, 2005). These may compound personal barriers, such as fear that substance use will be detected or presumed, fear of medical providers and procedures, prior negative experiences with the health system, and the belief in the "naturalness of pregnancy" (Long, 1998).



Urban AI/AN face several additional challenges when trying to access quality health care in general and maternal and child health services in particular. Documented challenges include time constraints, distrust of government programs, costs associated with travel to receive government-provided health care, and lack of transportation and child care (Kaiser Family Foundation, 2004; UIHI, 2009). Additionally, many of those seeking treatment at urban clinics are poor and uninsured, and Medicaid covers only part of their care (UIHI, 2009). A majority of urban AI/AN are not eligible for or are unable to utilize health services offered through the Indian Health Service or Tribes, so urban Indian health organizations (UIHO; see description in box below) are essential for this population (Urban Indian Health Commission, 2007). However, these urban programs receive only 1 percent of the Indian health budget and often struggle to obtain and maintain the funding, resources and infrastructure needed to serve the growing population of AI/AN, as described further in the next section.

URBAN INDIAN HEALTH ORGANIZATIONS (UIHO)

Urban Indian Health Organizations (UIHO) are private, non-profit corporations that are governed by Indian majority Boards of Directors and serve as service and social hubs for Indian identity and recognition in select cities. Today, UIHO are most often affiliated with contractual agreements with the federal Indian Health Service under Title V of the 1976 Indian Health Care Improvement Act. UIHO range in size and services from small information and referral sites to large community health centers offering medical and dental services and that are part of local safety net provider networks for the uninsured and poverty communities. UIHO serve individuals in approximately 102 U. S. counties in 19 states, and manage to provide services to more than 150,000 clients each year.

Often seen as centers for cultural activities and identity, UIHO offer AI/AN living in these urban areas a place where they can receive health information and services in a culturally appropriate manner.

In a 2006 survey of maternal, infant and child health services at UIHO, participating sites reported shortages in OBGYN providers and funding for related-services, and limited funding for an OB provider was also reported as a barrier to care for pregnant women (UIHI, 2009). Of the 23 sites that provided data on provision of services, the majority reported providing onsite and/or referral for pregnancy and infant health services such as pre/inter-conception care, immunizations, well-child visits and parenting support. However, between 22% and 35% of sites did not offer or refer clients for maternity case management, childbirth classes, home visits/public health nurse visits and SIDS counseling. Greater than 17% of sites did not offer or refer clients for newborn screening and lactation support. Also, the need for prenatal dental care providers was specifically mentioned by UIHO and was reported as an unmet need by both clients and providers. Studies show that mothers' oral health directly affects the outcome of their pregnancies and their infants' health (Jeffcoat, 2003; Offenbacher, 2003; Reed, 2003).

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Grossman and colleagues also concluded in an earlier study that although UIHO existed in most cities with large birth counts, many had inadequate resources to meet existing needs to improve perinatal outcomes and infant health (Grossman, 2002). Although direct medical care or outreach services for urban AI/AN are available, in some cases the amount of need for care and the services available were not necessarily compatible. For example, in the case of the Los Angeles-Orange metropolitan area, direct prenatal care services were not offered through an UIHO despite having the highest number of American Indian and Alaska Native births among metropolitan areas.



Variations by metropolitan status and region

Of the total U.S. population, 4.1 million (1.5%) identified themselves as being American Indian or Alaska Native on the 2000 U.S. Census, which includes Hispanic people who identify themselves as being of American Indian or Alaska Native descent, either alone or in combination with another race (US Census, 2000). Of the 4.1 million AI/AN, 2.5 million (0.9% of the total U.S. population) identified themselves as being solely American Indian or Alaska Native. The 11 states with the largest American Indian and Alaska Native populations were California, Oklahoma, Arizona, Texas, New Mexico, New York, Washington, North Carolina, Michigan, Alaska, and Florida.

Approximately 67% of AI/AN live in urban areas. Urban AI/AN are a very diverse group, and include members, or descendents of members, of many different tribes. Represented tribes may or may not be federally recognized, and individuals may or may not have historical, cultural, or religious ties to their Tribal communities. Individuals may travel back and forth between their tribal communities or reservations on a regular basis, and the population as a whole is quite mobile (Lobo, 2003). Urban AI/AN are also generally spread out within the urban center instead of localized within one or two neighborhoods, and thus are often not seen or recognized by the wider population.

Documented variations in birth outcomes among AI/AN residing in urban settings include a twofold increase in infant mortality rates from 1981–1990 among AI/AN living in an urban area (Grossman, 1994). Also, from 1995 to 2000, infant mortality rates among urban AI/AN were higher than rates for the corresponding general populations and did not decrease despite significant decreases in the general populations in the same urban areas (Castor, 2006).

Higher rates of low birth weight have also been reported among urban American Indian and Alaska Native infants compared to urban white infants (Grossman, 1994; Grossman, 2002; Baldwin 2002); and premature birth rates for urban AI/AN are higher than those of all races (13.8% of live births among AI/AN and 11.8% among all races in the same areas) (CDC, 2002-2006).

Regional differences are seen in Indian Health Service (IHS) data reports. The IHS reported an infant mortality rate for the service area population in 1999-2001 of 8.8 deaths per 1,000 live births. The rate among AI/AN was 28% higher than the rate for all races in 2000 (6.9 deaths per 1,000 live births). The two IHS Areas with the highest rates (Aberdeen: 13.4 and Alaska: 10.8 per 1,000 live births) exceeded the all races rate by over 50%; the lowest rate was in the Albuquerque area with a rate of 6.8 per 1,000 live births. These rates are adjusted for misreporting of American Indian and Alaska Native race on the state death certificate (U.S. DHHS, 2002-2003).

II. The Need

A regional analysis of infant mortality by Alexander et al also confirms that AI are not a homogeneous group in terms of birth outcomes. In their analysis, the 12 IHS areas were combined to form three regions: West, South/Northeast and Mid-West (Alexander, 2008). Using the West region as a reference group, the South/Northeast region had more low birth weight and very preterm problems and higher risk for mortality related to perinatal conditions. The Mid-West had the highest risks of infant mortality, with higher birth weight/gestational age specific mortality rates and higher risks for SIDS.



Although a recent publication cites an improvement in infant mortality rates among AI/AN in the Pacific Northwest between 1990-97, examinations of more recent data in this region (2000-04) using the Perinatal Periods of Risk approach, found an overall fetal-infant mortality rate (FIMR) for AI/AN of 13.0 compared to 7.6 per 1,000 live births in the reference group (CityMatCH, 2004; Gaudino, 2008; Barkan, personal communication, 2007; Pyle, 2008). The FIMR includes fetal and infant deaths occurring ≥ 24 weeks of gestation and birth weight ≥ 500 grams. The PPOR approach, a joint venture by the CDC, the Maternal and Child Health Bureau and CityMatCH, may be a promising method for further examinations of infant mortality among AI/AN within different regions, as it provides results that are simply communicated to community partners and promotes community-initiated interventions to address categorized risks by salient periods for a particular population. Among AI/AN in the Pacific Northwest, the periods with the highest contribution to excess or preventable fetal-infant deaths were infant health (excess rate of 4.64 deaths per 1,000) and maternal health/prematurity (excess rate of 0.96 per 1,000). These findings suggest the need for programs that support post-neonatal infant health, such as SIDS risk reduction, access to health care, injury prevention, maternal social support and a focus on pre-conception health, post-neonatal health behaviors, the need for early and continuous prenatal care services, and referral and management continuity for high-risk pregnancies.

Rates of late prenatal care and inadequate prenatal care utilization also varied by region and state both for AI/AN and for NH-whites in a recent study (Johnson, 2010). The Midwest generally had the widest AI/AN–white disparities for both indicators. When focused on the 12 states with the largest AI/AN birth populations, changes in disparities in prenatal care utilization varied dramatically, with some states showing substantial reductions in disparities and other states showing marked increases in disparities. Authors suggest that additional research is warranted to understand the causes and consequences of state-specific or local-area disparities in prenatal care utilization for AI/AN.

The variable rates of infant mortality, birth outcomes and risk factors among AI/AN nationwide suggest that consistent surveillance and in-depth examinations are needed to better understand what is causing these differences. It also suggests that a one-size fits all approach to addressing infant mortality among AI/AN may not be successful.

Socioeconomic, cultural and historical factors for AI/AN

The role of socioeconomic and other contextual factors for poor perinatal outcomes in AI/AN should be included in any effort to address infant mortality, as these broad, overarching factors affect communities regardless of geographic location or other individual risk factors. The socioeconomic disparities between AI/AN and the general population are well known, with high rates of unemployment and poverty and low levels of education among a host of other factors. Castor et al also found higher rates of disability, more single parent households, higher rates of poverty, lower levels of formal education, and higher unemployment among urban AI/AN (Castor, 2006).

II. The Need

The failure of a recent study to see an effect of neighborhood poverty on infant death among AI/AN highlights the challenge of isolating select risk factors from other interrelated factors for AI/AN, which are also independently associated with poor outcomes (Johnson, 2008). People in positions of lower relative socioeconomic status often have increased rates of high-risk behaviors, acute and chronic stress, depression and lower levels of social support (Williams, 2005). Among AI/AN for example, the conflict between the search for employment and social networks in other geographic areas, often results in poor social support and higher levels of stress. In one study of AI/AN in the Pacific Northwest, travel to reservations from urban areas was related to greater identification with Native culture and an absence of mental health problems, while urban living was associated with less social support (Rhoades, 2005).



In addition to the socioeconomic factors, the complex shared history of trauma from numerous incivilities done to AI/AN through federal policies enacting colonialism and cultural genocide, have had a lasting negative impact on traditional social networks among other issues, affecting all American Indian and Alaska Native communities (Brave Heart, 1998; Northwest Community Alliance, 2005). The reportedly decreased level of social support among AI/AN may be directly linked to poor health outcomes (Pearce, 2003).

American Indian and Alaska Native mothers also experience a disproportionate number of stressful life events during pregnancy; particularly as related to financial stressors and traumatic stressors (substance or physical abuse, incarceration, or homelessness) (Lu, 2004; Smith, 2008; Hutchinson, personal communication, 2009). Furthermore, chronic exposure to stressful life circumstances over the course of a woman's life increases the cumulative allostatic load hypothesized to impact birth outcomes (Lu, 2003).

The numerous risk factors for poor birth outcomes together with the unique political status, history and diversity of the American Indian and Alaska Native population underscores the importance of incorporating the multifaceted nature of infant mortality among AI/AN in any attempt to address it.

Data limitations for AI/AN

Historically, there has been a great amount of difficulty finding statistics on AI/AN; a difficulty that is exacerbated in urban settings (Cross, 2004). Racial misclassification is a common barrier in epidemiologic studies including AI/AN and almost always results in AI/AN being misclassified as Hispanic, Asian, or white (Cross, 2004). Similarly, racial misclassification consistently results in underestimates of disease-related morbidity and mortality (Stehr-Green, 2002). This is a rampant problem among birth and death certificates, disease registries, and schools. One study reported an estimated one-third of American Indian and Alaska Native children are misidentified or not identified correctly as AI/AN (Epstein, 1997). Though the Indian Health Service (IHS) and others have attempted to adjust rates to reflect a more accurate population count, there remains a need to standardize the method for calculating American Indian and Alaska Native population rates; a need that is unaddressed in state vital statistics records. These limitations should be considered when reviewing rates of infant mortality for AI/AN, as they are likely underestimated, and therefore downplay the true rate of infant mortality for AI/AN.

III. The Lessons

Health communication campaigns among AI/AN

There are a variety of activities, which could be used to address the significant disparities in infant mortality experienced by AI/AN. Some of these categories and examples of each in American Indian and Alaska Native communities include:

primary healthcare interventions for individual patients; an example is the federally funded Vaccines for Children program, which provides free vaccines for AI/AN (Teitelbaum, 1999);

community based interventions such as support groups with education on infant mortality and SIDS; an example is a traditional cradleboard class taught by the Native American Women’s Dialogue on Infant Mortality (NAWDIM) (see description of cradleboards in box below) (NAWDIM, n.d.), and

legislative interventions; such as the recent Patient Protection and Affordable Care Act: Maternal, Infant and Early Childhood Home Visiting Program, which provides infrastructure and support to States for a coordinated system of early childhood home visiting.

This section of the report is focused on another category referred to as *health communication campaigns*. The campaigns are not isolated efforts, but operate alongside the important work of health care providers, local and national activists, policy makers, and others who are involved in addressing the health of American Indian and Alaska Native communities. This review offers a snapshot of some of the more prominent health communication campaigns focused on AI/AN and brings together insights on their approaches to addressing the needs of AI/AN and ways of communicating with this unique population.

A cradleboard is a baby carrier used by American Indians and Alaska Natives to keep babies safe, secure and comfortable while at the same time allowing the mothers freedom to work and travel. They consist of a frame made of natural materials and are decorated with materials and in a style that varies from tribe to tribe. It is flexible in use, decorative and protective. Cradleboards should not be used in lieu of car seats.



Toy cradleboard image

Bison (*Bos bison*) Buckskin, wood, tradecloth, glass beads, hair. L 68.3, 31.2 cm

Image: National Park Service, Museum Management Program and Nez Perce National Historical Park, Toy Cradleboard, NEPE 1629. Available at: www.cr.nps.gov/museum.

III. The Lessons

Campaign review methods

There is often confusion with the terminology used for campaigns, for example language such as communication campaign or program, media or mass media campaign, and intervention are often seen in the literature. No particular definition adequately covers current practice, and there are many variations of what is meant by these terms. A variety of definitions exists in the literature, but the following elements of a communication campaign were used for the purpose of this review (Rogers, 1987):

- planned to generate specific outcomes;
- aims to reach a relatively large number of individuals;
- includes a specified time period; and
- uses an organized set of communication activities.

While communication campaigns specifically on infant mortality or infant health were the initial focus of this review, the limited number of campaigns on infant mortality prevention conducted among AI/AN led to the broader questions: What health communication campaigns have been conducted among AI/AN? What methods have they used to reach AI/AN? Have these methods been effective?

In order to gather data on communication campaigns among AI/AN, both published and grey literature databases were searched using the primary search terms: “American Indian”, “Alaska Native”, “Native American”, “health”, “promotion”, and “campaign”. Published literature databases searched included: Pubmed, Web of Science, Native Health Database, HealthComm and ERIC. Grey literature was sought from the following websites: Centers for Disease Control and Prevention, Indian Health Service, The Maternal and Child Health Library, Robert Wood Johnson Foundation and online search engines including Yahoo and Google.

This review includes national health communication campaigns among AI/AN in the United States. Reviewed campaigns reflect an array of diseases and health topics of focus, as well as approaches to communication with AI/AN. Campaigns were not limited by year, but only campaigns for which materials for AI/AN were available online for review or were well described in literature or reports were included. Therefore, this is not an exhaustive inventory of every health communication campaign conducted for AI/AN, but rather a collection of some of the more well-known and accessible national campaigns that employed a range of communication outlets directed at American Indian and Alaska Native audiences.

Campaign review findings

Description of campaigns

A total of 80 campaigns were reviewed. Fourteen (18%) of these were excluded based on unavailable materials for AI/AN or lack of information about communication efforts, another 21 (26%) were excluded because they only included one communication product or activity, such as a brochure, factsheets or a manual or they did not otherwise fit the defined criteria for a campaign and 13 (16%) were excluded because they were not directed to a national audience. After exclusions, there were 31 campaigns examined with 22 identified health topics. There were four campaigns directed to diabetes as a health topic, but other health topics were the focus of no more than two campaigns each. A table summarizing each included campaign can be found in the report’s appendix.

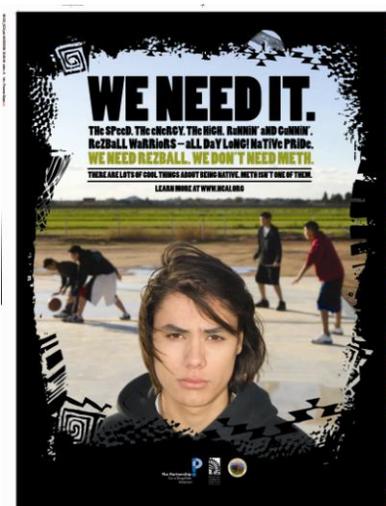


Image: Office of National Drug Control Policy, U.S. Department of Health and Human Services, U.S. Department of Interior's Bureau of Indian Affairs, Partnership for Drug-Free America and the National Congress of American Indians.

III. The Lessons

A majority of campaigns (N=21; 68%) were conducted by government agencies such as the CDC (n=9); five (16%) were conducted by Native non-profit agencies such as the Northwest Portland Area Indian Health Board; four (13%) were conducted by advocacy or philanthropic agencies such as the Robert Wood Johnson Foundation and the March of Dimes, and one (3%) was conducted by an academic institution.

The years of campaign implementation were of a wide range starting from the earliest “Stop Baby Bottle Tooth Decay” started in 1984 up to the most recent “Native American Anti-Meth Campaign” implemented in 2010 (see poster on previous page).

There were a variety of audiences targeted in the campaigns examined. Nine (29%) campaigns were directed to the general American Indian/Alaska Native population, seven (23%) were focused fully or in-part on youth and six (19%) were focused fully or in-part on parents. Women, health professionals, educators, patients and elders make up the other target audiences (29%).

Based on the definition used for our review, each campaign included at least two communication activities or material types to reach AI/AN. A couple of campaigns used as many as nine activities/materials, such as the Baby Bottle Tooth Decay campaign, which incorporated posters, a PSA, newspaper articles, educational materials, training manuals, events, counseling booklets, tippee cups, and bumper stickers. A few campaigns used as few as two activities/materials including the “Common Infection Common Reality” campaign on human papillomavirus or HPV, which involved a series of posters and brochures. Overall, the most frequent outreach activity/material used was posters (N=18; 58%). The least frequent activity/material was billboard ads (N=2; 6%), which likely reflects the relatively high cost of this outreach method.

American Indian and Alaska Native specific campaigns

Of the 31 included campaigns, thirteen (42%) campaigns were developed specifically for American Indian and Alaska Native audiences; of these four were developed by a Native non-profit organization and three were developed by IHS. One example of a campaign developed specifically for AI/AN is the Native Diabetes Wellness Program, which includes a goal of sharing stories and art about survival and traditional ways of health.

Another eleven (35%) campaigns had a segment for AI/AN within a larger campaign for the general population, but were not initially developed solely for AI/AN. One example of this is the “Parents Speak Up” national campaign to promote discussion about sex between parents and their children (see poster on this page). The U.S. Department of Health and Human Services contracted with a Native agency to help generate a grassroots effort among AI/AN nationwide that incorporated relevant activities such as a talking circle as a support for parents. Another example which would fall under this category in our review once completed, is the “A Healthy Baby Begins with You” campaign, by the Office of Minority Health, which has contracted with the Seattle Indian Health Board’s Urban Indian Health Institute, an American Indian/Alaska Native community-based organization, to develop and pilot a campaign for infant mortality among AI/AN.

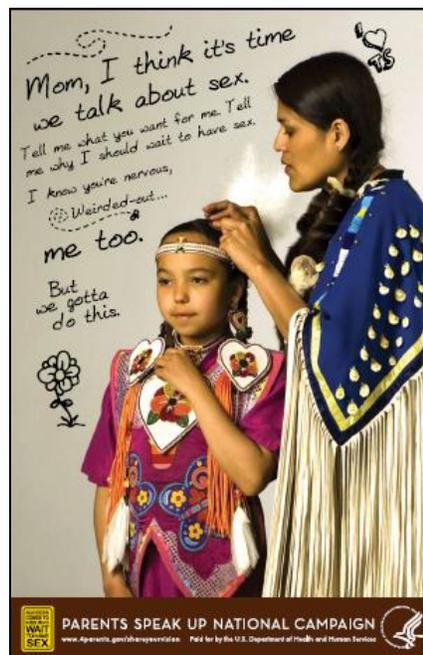


Image: U.S. Department of Health and Human Services, Native American Outreach Center.

III. The Lessons

Four (13%) campaigns developed one or two select products specific to American Indian and Alaska Native audiences, such as a brochure or poster. In one example, the IHS with permission from the Partnership for Clear Health Communication, modified the “Ask Me 3” campaign materials on health literacy to incorporate photos of AI/AN (and these were posted on the IHS website), but there were no further modifications for AI/AN. Similarly, “The Heart Truth” campaign on heart disease included AI/AN in photos of women wearing the campaign signature red dress and had stories of American Indian women’s struggles with heart disease in their online series, “Stories from the Heart”.

Formative research with AI/AN

Formative research in campaign development is as important, if not more important, than evaluations after a campaign (Rogers, 1987). While studies may describe the preparation of regional or Tribe-specific educational materials, national evaluation of diverse American Indian and Alaska Native group preferences for materials is often lacking. Information about formative research conducted among AI/AN was accessible online for 14 (45%) of the campaigns reviewed. Methods ranged from in-depth focus groups and interviews with multiple segments of the American Indian and Alaska Native audience in the Centers for Disease Control and Prevention’s (CDC) “VERB” campaign on physical activity among youth (see poster on this page), to convening an expert panel including representatives from American Indian and Alaska Native organizations and other community members, such as in the “Move It! And Reduce Your Risk of Diabetes” campaign (see poster on this page), and the “Covering Kids” national campaign to connect uninsured children to health care coverage. Published findings from focus groups with Tribal leaders, Indian health professionals and American Indian and Alaska Native community members in the development of materials for AI/AN for the National Diabetes Education Program reported that 95% of participants expressed a strong preference for materials relevant to their specific tribe or culture (Roubideaux, 2000).

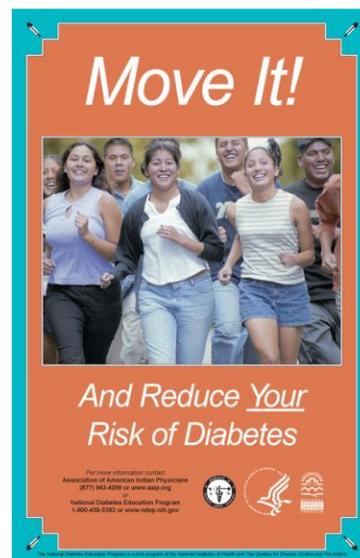


Image: U.S. Department of Health and Human Services, National Diabetes Education Program, Association of American Indian Physicians.

Evaluation with AI/AN

Sixteen (52%) campaigns did not have evaluations available in our search and four (13%) did not have evaluation findings for AI/AN specifically. Eleven (35%) campaigns did have an evaluation component, and outcomes for AI/AN were located for nine of these. Evaluation activities varied widely across reviewed campaigns from defined measures and outcomes at each project phase to qualitative success stories shared by program participants or program activities highlighted on an online blog forum. Below are descriptions of two successful campaigns with important lessons for future efforts among AI/AN.

The CDC’s VERB campaign was funded directly by a U.S. Congress mandate at \$125 million for the first



Image: U.S. Department of Health and Human Services’ Centers for Disease Control and Prevention.

year alone (see poster on this page). In four subsequent years funding went no lower than \$36 million per year. Since a limited budget is often a major reason for lack of quality evaluation activities, the substantial funding and commitment to investing in evaluation put the campaign in a unique position to describe the

III. The Lessons

campaign's effectiveness in detail. The VERB campaign's evaluation activities included formative, baseline, process, and outcome measures, and findings are shared in multiple peer-reviewed publications (Wong, 2008). In addition to the outcomes on individual awareness and behavior changes, the VERB campaign shared findings on the process and outcomes of vital partnerships developed with community organizations through the project. The campaign understood well the need to work on upstream structural changes to assist communities in removing environmental and other barriers to physical activity.

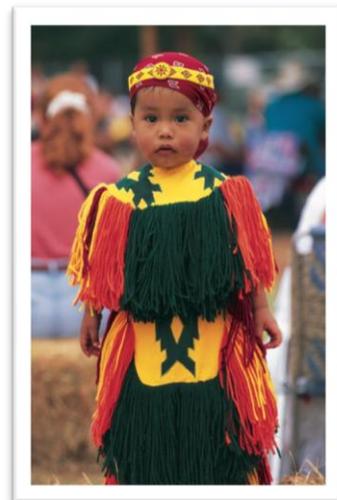
Another successful campaign with a much lower budget, the 1984 "Baby Bottle Tooth Decay" (BBTD) campaign (see poster on this page) utilized in-kind and volunteer services rather than compromise the integrity of their desired interventions. Staff members added volunteer project tasks to their job responsibilities, which carried positives and negatives. On one hand, clinic staff members are often already over-worked in under-funded positions. On the other hand, community ownership of the project led to an individualized program at each pilot site and cooperative networks across communities and organizations. The BBTD campaign planners encouraged tailoring educational materials and strategies to fit each community. Preliminary results documented statistically significant decreases in the prevalence of BBTD at the pilot sites. This multidisciplinary, comprehensive intervention offers a model for organizing communities to prevent health problems (Bruerd, 1989).



Image: U.S. Department of Health and Human Services, Administration for Children, Youth, and Families, Head Start Bureau; Indian Health Service; and Centers for Disease Control and Prevention

IV. The Efforts

Select efforts to address SIDS and infant health among AI/AN are summarized here with the goal of learning about potential promising practices for a future national infant mortality campaign as well as any challenges to avoid. Also, over-time consideration of linked or similar campaigns is important in assessing the longer-term effectiveness of campaigns to address a health problem (Rogers, 1987). It is important to determine whether repeated campaigns are achieving net gains, maintaining the status quo, having no effect, or in fact having a negative effect and to build on the clear areas of success.



Healthy Native Babies Project

The National Institute of Child Health & Human Development met with American Indian and Alaska Native stakeholders and federal partners in 2002 to address the high SIDS rates among AI/AN. A work group was formed to create an outreach initiative focusing on the Northern Tier of the U.S, where SIDS rates are the highest for AI/AN. This area includes five IHS Service Areas: Aberdeen, South Dakota; Anchorage, Alaska; Bemidji, Minnesota; Billings, Montana; and Portland, Oregon. The *Healthy Native Babies Project* was created to develop culturally appropriate SIDS risk-reduction messages for American Indian and Alaska Native families. The project was also designed to provide local support and offer training to healthcare providers and community health and outreach workers. A *Healthy Native Babies Project Workbook* and Toolkit were developed and utilized during train-the-trainer sessions, conducted with 232 attendees in 2006-07. The Workbook covers topics including: facts about SIDS; strategies for reaching communities; action steps to reduce SIDS; and planning and sustaining projects. The Toolkit allows users to develop custom education materials with SIDS risk-reduction messages that have images of AI/AN and Native languages from their locale.

A mini-grant program provided 26 grantees with \$2000 each to develop outreach materials such as brochures, posters, printed onesies, flyers, printed bibs, postcards and “Welcome Home” bags filled with pamphlets, books, and baby necessities. The project also provided resource stipends to 10 organizations during 2009 which allowed Tribes and organizations to create materials from the *Healthy Native Babies Project Toolkit* or select activity materials that were used during the trainings. Some of the activities conducted with the stipends included:

- Community baby showers for pregnant women with transportation, child care, lunch and presentations on topics such as SIDS and breastfeeding;
- A two-week long cradleboard class to address SIDS with moms, dads and grandmothers and invited elders to participate in the last day of class, which included a meal and a blessing of the cradleboards with sage; and
- Presentations to families with photographs of babies provided as gifts to participants.

Next steps for the *Healthy Native Babies Project* include: disseminating project materials; developing strategies for gaining support from Tribal leadership in the Northern Tier; creating an online self-study module; and offering resource stipends to Tribes and organizations.

SIDS Risk Reduction Resource Kit for American Indians and Alaska Natives

In 2003 the U.S. Department of Health and Human Services (U.S. DHHS) teamed up with the CJ Foundation to launch a public-private partnership aimed at reducing the risk of SIDS in Indian Country. Other members of the coalition included the Association of American Indian Physicians and the Smoke-Free Families National Dissemination Office. The CJ Foundation and U.S. DHHS awarded grants for development of the project to three American Indian organizations: Great Lakes Inter-Tribal Council,

IV. The Efforts

University of North Dakota Fetal Alcohol Syndrome Center and Aberdeen Area Tribal Chairmen's Health Board. The organizations used the funding to develop culturally competent educational materials that address the unique SIDS prevention needs of American Indian and Alaska Native communities.



These materials were made available to all health professionals who work with Native populations. The CJ Foundation contracted with Okiciya Consulting/KAT Communications to collect and incorporate them into an American Indian and Alaska Native SIDS Risk Reduction Resource Kit that was distributed nationally. From the production of 10,000 kits, about 7,000 were distributed to health agencies and providers of AI/AN and worldwide. Okiciya provided the distribution services and ongoing messaging and awareness media to facilitate distribution of the remaining kits, which were offered free of charge through the CJ Foundation for SIDS website. The kit, which is designed to be Pan-Indian rather than Tribe-specific for the widest possible use, includes:

- A 24-page training and resource manual that health educators can use to conduct one-on-one counseling and classroom education;
- Two videos, “Saving Indian Infants from Dying in Their Sleep” and “SIDS Awareness Project,” in both VHS and CD-ROM formats; and
- A CD-ROM containing culturally appropriate posters, brochures, public service announcements and other educational materials that can be distributed to AI/AN to spread awareness about SIDS prevention.

The Coming of the Blessing

An initiative begun in 2007 by the March of Dimes aims to address disparities in birth outcomes for AI/AN using a perinatal education booklet and adaptation of a perinatal education curriculum for AI/AN. A committee of primarily American Indian women representing 10 different tribes conducted focus groups with providers and patients, reviewed existing educational materials and evaluated a prenatal education project conducted on the Wind River Reservation in Wyoming. Based on these findings, they created *The Coming of the Blessing* booklet, which is now used as a teaching tool in 13 states. More than 7,000 booklets were distributed to targeted AI/AN communities during the pilot project. To date, women from more than 30 tribes, Nations and pueblos have received *The Coming of the Blessing*. Evaluation data is being collected from families and providers. Based on the evaluation, the booklet will be modified and more widely distributed.

Through this 28-page booklet, the American Indian symbol of the Medicine Wheel is used to describe the cycle, including preparation for pregnancy, each trimester of pregnancy and infant care. The booklet is designed to be used as a teaching tool in conjunction with prenatal education sessions that have been adapted to address cultural beliefs that impact pregnancy and parenting. *The Coming of the Blessing* Initiative combines the booklet with a new March of Dimes prenatal education curriculum called *Becoming a Mom*. *Becoming a Mom* includes an appendix that helps facilitators adapt the basic prenatal health information for an American Indian audience.

V. Conclusions

There are numerous lessons to take from the previous health communication campaigns conducted with AI/AN, which will inform the development of a new campaign for raising awareness and ultimately reducing rates of infant mortality among AI/AN.

Conduct formative research with AI/AN

Campaigns with previously developed materials are often adapted to include American Indian or Alaska Native images or symbols, but formative research to learn about the target community, effective messages and communication channels to best reach AI/AN is done less often. This work is critical to improve the effectiveness of a campaign by producing messages that are specific to the desired audience and behavioral change.



Incorporate American Indian and Alaska Native cultural concepts and practices

Respectful and appropriate integration of cultural concepts and practices into health communication may require more than simply using American Indian and Alaska Native images or symbols on campaign materials. One report by the American Indian Policy Institute suggests that while differences among communities exist, American Indian and Alaska Native values and beliefs can still be effectively incorporated into programs through universal American Indian and Alaska Native practices such as “oral teachings” and “learning by observing and through experience” (Becker, 1998). Also, an emphasis on strength-based concepts such as cultural sovereignty, self-determination, spirituality and other practices is an effective way to counteract the historical trauma and cultural degradation that has impacted AI/AN (National Healthy Marriage Resource Center, 2010). Meaningful dialogue and ongoing involvement with target communities is needed to help ensure cultural responsiveness and sustainable efforts.

Develop campaign in partnership with American Indian and Alaska Native communities

American Indians and Alaska Natives are a diverse population, representing over 560 different tribes with varied histories and traditions (U.S. Census, 2000). Any project describing AI/AN as a whole poses the risk of masking the rich variety of customs, lifestyles and politics that have shaped AI/AN and cannot be generalized. Furthermore, American Indian and Alaska Native communities continue to change through intermarriage and interactions with other communities and cultures. No single project can address all of the needs of the diverse populations of AI/AN nor uniformly describe the dynamic nature of their communities. Local program providers and community leaders are most closely acquainted with the needs of their specific communities, and should be included in development and tailoring of materials to fit the mores and customs of the populations they serve and also to incorporate sustainability into the efforts.

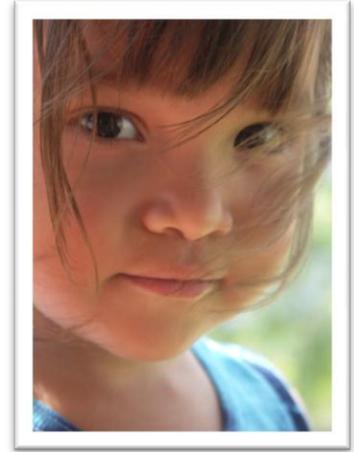
Set realistic expectations for health communication campaign outcomes

The ‘hierarchy of effects’ matrix developed by McGuire proposed that only about 50% of an audience will recall the media message, about half of those will understand the message, half again will accept it as relevant, half again will shift attitudes, half of those will adopt the new behavior, half will try it, and half again will maintain the new behavior. Thus, the role of a communications campaign is more likely to be effective in increasing salience of a campaign message rather than achieving behavioral changes (McGuire, 1984). Though, modest changes in audience behavior are achievable, and it is important to set modest and realistic expectations about what can be achieved.

V. Conclusions

Ensure adequate resources and methods for useful evaluation and dissemination of results

Campaign activities should be clearly focused on the exact outcomes that are feasible, achievable and measurable. Further, dissemination of campaign evaluation results is vital to enable others to learn from previous campaign successes and failures. Healthy People 2010 objectives also include an increase in the proportion of health communication activities that include research and evaluation (U.S. DHHS, 2000). However few studies evaluating outcomes include AI/AN, and projects are often not funded beyond the development and dissemination of materials. Campaign plans for the diverse American Indian and Alaska Native population should include adequate resources and methods to achieve useful campaign evaluation in multiple settings.



Support campaign with activities that address upstream and downstream factors

Long-term behavioral change induced by campaign messages alone is unlikely to be successful; therefore other supportive interventions are essential. These may involve direct, personal interventions or community-based interventions like some of the examples described in earlier sections of the report. Further, infant mortality among AI/AN should be viewed in light of its social, cultural and political context with efforts at addressing upstream factors. However, organizations planning health communication efforts rarely have the resources or political power to address these larger issues that are closely related to infant mortality. Funds should be made available to support direct care for AI/AN, as well as efforts to address underlying factors for AI/AN wherever they reside.

- *Conduct formative research with AI/AN*
- *Incorporate American Indian and Alaska Native cultural concepts and practices*
- *Develop campaign in partnership with American Indian and Alaska Native communities*
- *Set realistic expectations for health communication campaign outcomes*
- *Ensure adequate resources and methods for useful evaluation and dissemination of results*
- *Support campaign with activities that address upstream and downstream factors*

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VII. Appendix

Campaign Title	Campaign Organization	Campaign Description	Campaign methods
AI/AN Pre-teen Vaccine Campaign	Centers for Disease Control & Prevention (CDC)	Educate parents and providers about recommended pre-teen vaccines for Human papillomavirus (HPV) and the 11 and 12 year old medical check-up.	Website, flyers, posters, web buttons
Ask Me 3	Partnership for Clear Health Communication	Promote patient-initiated communication and health literacy by encouraging patients to ask questions.	Resource kit, including, fact sheets, information sheets, brochures, posters, resource list
Common Infection Common Reality	CDC	Help individuals and health care providers understand HPV, its prevention, and its consequences.	Website, brochure
Control Your Diabetes for Future Generations	National Diabetes Education Program (NDEP)	Promote awareness of risk of type 2 diabetes for prevention.	Brochures, posters
Covering Kids & Families	Robert Wood Johnson Foundation	Connect uninsured children to health care coverage.	TV, print and radio PSAs, posters, interventions and activities
Fetal Alcohol Spectrum Disorder Resource Kit	Substance Abuse and Mental Health Services Administration (SAMHSA)	Educate Healthy Start staff to help prevent Fetal Alcohol Spectrum Disorder (FASD) among AI/AN/NH.	Toolkit with templates for brochures, posters, flyers, PSAs, letters, article
Get Smart: Know When Antibiotics Work	CDC	Promote adherence to appropriate antibiotic prescribing guidelines and decrease in demand for antibiotics by patients.	Brochures, posters, factsheets, instructional sheets, guidelines, press kit
Healthy Native Babies	National Institute of Child Health & Human Development	Educate the Northern Tier AI/AN communities about Sudden Infant Death Syndrome (SIDS).	Brochure, poster, flyer, postcard, CD, workbook, training/education
Honoring the Gift of Heart Health	National Heart, Lung, & Blood Institute (NHLBI)	Education for AI on heart healthy living.	Booklet, video, training manual and CD
Just Move It	Native Health Communities Partnership	Promote physical activity for AI/AN.	Success stories, events, factsheets, resource materials, exercise programs, website

VII. Appendix

Campaign Title	Campaign Organization	Campaign Description	Campaign methods
Life is a delicate balance	CDC	Provide resources for State, Local, Tribal, and Territorial Health Officials on H1N1 Flu (Swine Flu)	PSA, posters, resource guide
Move it! And reduce your risk of Diabetes	National Diabetes Education Program	Encourage physical activity in the school setting to help reduce risk for diabetes among AI/AN youth.	Toolkit including posters, factsheets, model school programs
National Native HIV Testing Media Campaign	Northwest Portland Area Indian Health Board	Promote routine HIV testing.	Posters, flyers, radio PSA, window cling, print ad, web banner, t-shirts
National Native HIV/AIDS Awareness Day	US Department of Health and Human Services (US DHHS)	Create awareness of HIV/AIDS risk, call for resources, and eventually decrease HIV/AIDS among Native people.	Awareness day, website, letters from politicians
Native American Anti-Meth Campaign	Office of National Drug Control Policy	Prevent methamphetamine use among Native Americans.	Posters, billboard ads, TV commercials, radio ads, PSAs
Native Diabetes Wellness Program	CDC	Support community efforts to promote health and prevent diabetes.	Website, children's books and outreach campaign, traditional foods grant, articles, posters, DVD, program tutorial, culture-card
Native Vision	John Hopkins University and National Football League Players Association	Cultivate the core strengths, values and positive relationships for American Indian youth that will make them resilient to the prevailing risks.	Media workshops, summer camp, print, radio and TV ads, physical fitness, after-school recreation, case management, events, scholarships
Parents Speak Up	Native American Outreach Center	Encourage parents to talk to their children about sexuality and the importance of waiting to have sex.	Poster, factsheet, commitment card, website, community outreach kit, talking circle guide
Protect the Circle of Life: Immunize Our Children [Nations]	CDC	Encourage child immunizations.	Website, brochures, posters, journal articles
Ride Safe Child Passenger Safety Program	Indian Health Service (IHS)	Promote the use of child restraint devices to reduce motor vehicle related injuries to children in Tribal Head Start programs.	Training, program manual, car seat/booster seat

VII. Appendix

Campaign Title	Campaign Organization	Campaign Description	Campaign methods
Screen For Life: The National Colorectal Cancer Action Campaign	CDC	Inform men and women aged 50 years or older about the importance of having regular colorectal cancer screening tests.	TV and radio PSAs, brochure
SIDS Risk Reduction Resource Kit for AI/AN	CJ Foundation for SIDS and US DHHS	Reduce the risk of SIDS in Indian Country.	Training and resource manual, videos, CD-ROM with posters, brochures, radio PSAs
Stop BBTD (Baby Bottle Tooth Decay)	IHS, US DHHS, and CDC	Prevent baby bottle tooth decay and reduce use of a bottle past age 1.	Posters, PSA, newspaper articles, educational materials, training manuals, events, counseling booklets, tippee cups, bumper stickers
The Coming of the Blessing	March of Dimes	Address high rates of infant death and premature birth among AI/AN.	Booklet, poster, training, evaluation, curriculum adaptation
The Heart Truth	NHLBI	Promote heart disease awareness to women.	Pictures, online stories
The Sleep Safe Fire Safety Program: Mobilizing Communities in Fire Safety	IHS	Address the fire/burn injury problem among young children and ensure that AI/AN families are protected from the danger of a house fire.	Manual, curriculum, smoke alarms, program coordinator training
Together We Are Stronger	National Native American AIDS Prevention Center	Address homophobia and HIV stigma in AI/AN/NH communities.	TV and radio PSAs, posters, stories
Urban Indian C.A.R.E.S. (Colon and Rectal Education and Screening)	Urban Indian Health Institute, Seattle Indian Health Board	Promote education, testing, and treatment of colorectal cancer for urban AI/AN.	Media toolkit, factsheet, posters, postcards
VERB It's what you do.	CDC	Encourage tweens to be physically active every day.	Posters, TV, radio, billboard, print articles
What a difference a friend makes	SAMHSA	Encourage, educate, and inspire people between ages 18 and 25 years to support their friends who are experiencing mental health problems.	Radio ads, posters, brochure, banner
You Have the Power to Prevent Diabetes	National Diabetes Education Program	Promote healthy lifestyle changes to prevent diabetes.	TV, print and radio PSAs, posters, Tribal-based interventions/activities

