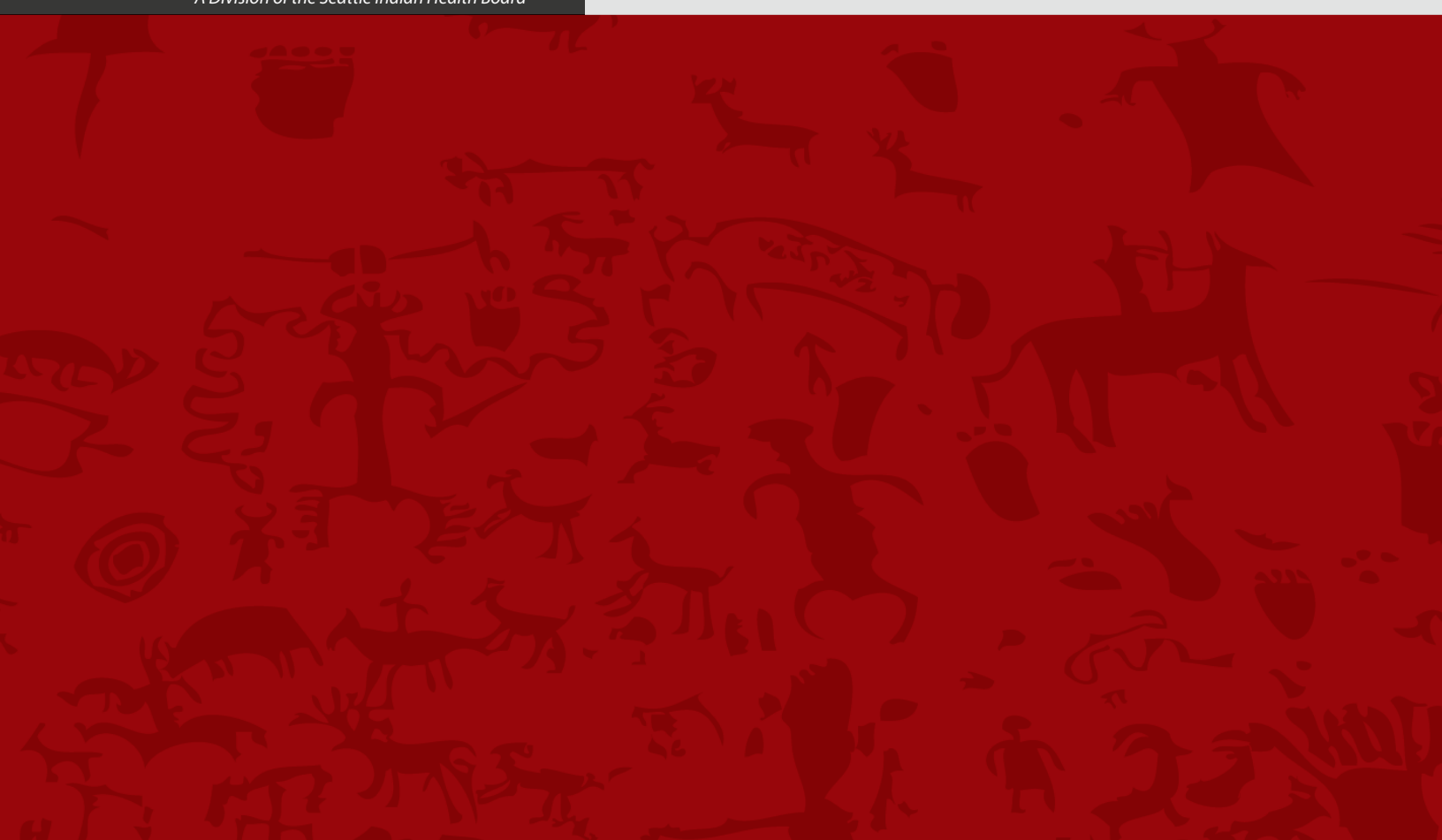




**Discussions with Urban American Indian
and Alaska Native Parents: Keeping Babies
Healthy and Safe**

May 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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Introduction

The qualitative research project described here was designed to gather opinions and insight from American Indian and Alaska Native (AI/AN) parents about “keeping babies healthy and safe” and effective messages and communication channels for information on these topics. The project took place in four urban communities nationwide. In this report we describe the results obtained from focus groups and individual discussions, which will be used in the development of a communications campaign to address high rates of infant mortality among AI/ANs in urban areas and beyond.

Background

The majority of AI/ANs reside in urban areas and experience striking disparities in infant mortality and maternal and child health compared to the general population (Castor, 2006). Current approaches to addressing infant mortality may not be entirely appropriate for urban AI/ANs who have unique exposures, barriers and experiences with regard to factors such as healthcare access, cultural identity and support systems (UIHI, 2011).

Methods

This project was carried out using group and individual discussions with AI/AN parents in four urban areas nationwide: Detroit, Michigan; Sacramento, California; Salt Lake City, Utah; and Seattle, Washington. Three of which are in states with some of the largest AI/AN populations in the U.S. (California, Washington, and Michigan). Discussions explored critical themes regarding the concept of “keeping babies healthy and safe”, including the barriers and facilitators to health and safety practices, as well as effective health messages and communication channels for sharing information on these topics with AI/ANs. The study was reviewed and deemed exempt from oversight by the National Indian Health Service Institutional Review Board.

Study Sites

The four study sites, referred to as 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. 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. Urban Indian health organizations 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. Urban Indian health organizations serve individuals in approximately 102 U. S. counties in 19 states, and manage to provide services to more than 150,000 clients each year.

Detroit. The American Indian Health and Family Services (AIHFS), founded in 1978, is a non-profit health center serving the AI/AN community of Southeastern Michigan. The AIHFS provides comprehensive health care services integrating traditional AI/AN healing and spiritual practices with contemporary western medicine in both treatment and prevention. The Native Healthy Start Program, which coordinated study activities, focuses on reaching at-risk pregnant women and providing access to prenatal care, counseling, education, coaching and encouragement. (www.aihfs.org)

Sacramento. The Sacramento Native American Health Center, Inc. (SNAHC) is a community-owned and operated Federally Qualified Health Center (FQHC) providing comprehensive health care services in Sacramento, California. The health center is committed to enhancing the quality of life by providing a culturally competent, holistic, and patient-centered continuum of care. Home visitation services, discussed in the findings, are provided through the American Indian Infant Health Initiative to vulnerable

AI/AN families who are currently pregnant or parents/legal guardians (including fathers, grandparents, etc.) who have children under 5 years old. (www.snahc.org)

The Shingle Springs Band of Miwok Indians opened the Shingle Springs Tribal Temporary Assistance for Needy Families (TANF) (SSTT) Program in 2010, which now provides support and assistance to AI/ANs and their families residing in El Dorado, Placer and Sacramento Counties in California. The SSTT Program incorporates culture and traditions into all aspects of the program in order to strengthen and solidify AI/AN families and assist in addressing and resolving issues, which create barriers to self sufficiency. The Fatherhood is Sacred program at SSTT, which hosted the dads discussion, offers free weekly confidential meetings led by a trained facilitator. The group supports men in a fathering role, stepdads, uncles, brothers and grandfathers, and promotes employment, positive parenting skills and healthy relationships. The group also identifies and values what makes AI/AN men special. (www.shinglespringsrancheria.com)

Salt Lake City. The Indian Walk-In Center (IWIC), located in Salt Lake City, Utah, has served for over 30 years as a gathering place where people can come to participate in familiar AI/AN community activities. The IWIC provides a wide range of wellness and social life-way services directly through their own programs and by working closely with many non-profit service organizations. Services include a diabetes wellness program, youth wellness program, health promotion and disease prevention, HIV/STI counseling and testing, adult substance abuse treatment, mental health counseling, eligibility support, food services and referral to Community Health Centers Inc. for primary healthcare and other services. (www.iwic.org)

Seattle. The Seattle Indian Health Board (SIHB), founded in 1970, is a multi-service non-profit community health center and FQHC dedicated to improving the health and well-being of urban Indians living in the greater Seattle-King County area. Services include: Primary clinical services and dental care, maternal and infant health, Special Supplemental Nutrition Program for Women, Infants and Children (WIC), home visits, pharmacy, community services such as youth, elder, mental health and domestic violence, in and out-patient chemical dependency, and traditional native health. (www.sihb.org)

Participants

A total of four focus groups and four interviews were held at the four study sites; four focus groups with moms, 1 focus group with dads and four individual interviews with dads. Participants were recruited through the study sites using flyers, as well as through word of mouth. Potential participants were informed that participation in no way affects their eligibility for health care services from the sites.

Discussions were scheduled at days and times which were most appropriate for each community and lasted between 1 and 2 hours (individual discussions were shorter than group discussions). Childcare, food and financial reimbursement were provided to participants. Written informed consent was obtained from each participant.

Parent Discussions

The aim of the discussions was to obtain information on AI/AN parental opinions and experiences around the concept of “keeping babies healthy and safe” in order to aid in the design of a communication campaign on infant mortality prevention. Each discussion was structured around a set of predetermined open-ended questions (available upon request). Further probing was adopted so as to ensure certain topics were addressed in sufficient depth during each session. The focus group/interview questions were reviewed by each study site. Discussion facilitators were AI/ANs and Maori with experience working with the AI/AN community. Separate discussions were held with moms and dads.

Focus group questions were designed to explore AI/AN parental perceptions, concerns, behaviors, barriers, facilitators, sources of trusted information, and support for keeping babies healthy and safe and effective messages and communication channels for sharing information on these topics. Questions were neutrally worded to minimize response bias (e.g., “What does the term ‘healthy and safe baby’ mean to you?”).

Data Analysis

The discussions were recorded and transcribed. The transcripts were coded into themes, which were grouped into sections that broadly aligned with the themes addressed in the discussion questions. Sub-themes were created for select topics, which were discussed in more depth by participants. Some broad themes emerged outside the topics in the discussion guide, which address overarching topics. Themes are also further categorized loosely into aspects such as context (physical, emotional, environment) or benefits and challenges, to provide an additional framework to further understand the experiences and opinions described by participants.

Participants’ own words are quoted extensively to support the themes that emerge, and to provide added depth and richness to the analysis. Project members who were present at the discussions had the opportunity to review the codebook, to provide additional perspectives on the code structure and to make sure that all pertinent topics were included. In order to organize and retrieve coded data, transcripts were entered into Atlas ti, a software package for analyzing qualitative data.

Findings

All thirty-nine of the participants completed a survey used to collect background information on socio-demographics (Table I below), tribal affiliation, county of residence, healthcare access, media use and sources for general health information (included in Appendix A).

TABLE I: Participant Demographic Information

Characteristic	Moms Number (%) (N=27)	Dads Number (%) (N=12)
<i>Average Age in Years*</i>	26.8	28.8
<i>Marital/relationship status</i>		
Single	10 (38%)	4 (33%)
Living together, but not married	6 (23%)	5 (42%)
Married	7 (27%)	1 (8%)
Divorced	3 (11%)	2 (17%)
<i>Employed</i>		
Yes	10 (38%)	4 (33%)
No	16 (62%)	8 (67%)
<i>Income</i>		
Less than \$25,000	14 (66%)	7 (63%)
\$25,001- \$40,000	4 (19%)	3 (27%)
\$40,001-\$55,000	1 (5%)	1 (9%)
\$55,001-\$70,000	0 (0%)	0 (0%)
Over \$70,000	2 (10%)	0 (0%)
<i>Education</i>		
Grades I through II (Elementary and/or High School)	8 (30%)	2 (17%)
Grade 12 (High school graduate or GED received)	5 (19%)	4 (33%)
Some college or AA (Technical/Vocational/Academic)	12 (44%)	4 (33%)
BA, BS (college degree)	0 (0%)	2 (17%)
Graduate or professional degree	2 (7%)	0 (0%)

Percentages based on number of responses in each category; variances are due to rounding

“Decline to answer” and “Don’t know” responses are excluded from table

*Ages ranged from 18-43 years for moms and 21-33 years for dads

On the following pages, discussion findings are outlined into sections within which themes are described for both moms and dads. Unique themes or contrasts between moms’ and dads’ discussions are also described.

SECTION 1: Healthy and Safe Baby Concept

Physical- When asked generally about what the term “healthy and safe baby” means to them, many comments on the physical aspects of a healthy and safe baby were focused on nutrition; one or two mentioned breastfeeding. Other comments addressed access to healthcare and information, immunizations, proper development, lack of illness, use of a car seat and prenatal care and wellness. Dads also noted the baby having everything it needs.

Emotional- Comments on the emotional aspect of the concept included generally a happy and loved baby, and parenting such as positive support, healthy expectations, having a routine and following it, and taking care of the baby as best as you can.

Environment- Many participants commented on the environment of the baby rather than direct physical or emotional aspects. These included generally a healthy/safe/stable environment and home, and more specifically a drug and alcohol free home. Comments also focused on the baby being with the mom, protected, around the right people and not exposed to unnecessary negativity or emotions.

"When I think of a healthy baby, it's one that's well fed, taken care of, loved, free not to be around alcohol or cigarettes, smoking, drugs."

Words, Actions and Images- When asked to describe words, actions and images associated with the term “health and safe baby”, many moms expanded on safety actions to protect the baby such as baby-proofing, use of car seats and not leaving baby alone; some moms and dads mentioned a physically active, playful baby and a curiosity to explore. Other comments focused on parents/caregivers such as sharing values for baby, working together, and generally taking advantage of available resources. The health and protection of the mom so she can take care of the baby was also noted by both moms and dads. One discussion revolved specifically around moms having the courage, education, resources and support to stop violence against them. This theme is addressed further in the Health and Safety Activities and Behaviors section.

"Everybody involved in that child's life working together to ensure that they're in a safe environment..."

SECTION 2: Health and Safety Activities and Behaviors

Physical- Many comments on the physical aspects of health and safety activities and behaviors were similar to those noted in Section 1; however, participants expanded on the previous themes of nutrition and breastfeeding.

Nutrition- Dads' comments about nutrition were focused on benefits, while challenges were noted by moms, like lack of resources to afford healthy foods and differing norms with their family and community members.

"Even with the fruits and vegetables and stuff, I don't have any money."

"When she goes to my mom's house, my mom just wants to feed and feed and feed and feed"

Breastfeeding- Discussions of breastfeeding included general benefits like health and strength, immunity, emotional support for mom and comfort for baby. Also discussed were sources of support used to help maintain breastfeeding like a faith healer, lactation consultant, online information on medications to avoid, Native Healthy Start and messages such as "one day at a time", and pervasive pro-breastfeeding campaigns. Mom's also offered more specific logistical benefits like don't have to get out of bed, no bottles to boil, helps get babies to sleep, smaller stools, less burping and cheaper than formula, although the fact that WIC provides formula was also noted. One mom described a radio ad on breastfeeding and weight loss after childbirth as a positive message with new information.

"Most Native American women breastfeed. And it can kind of sort of be hard, because some people give up and give them formula. But breastfeeding is much more healthier for them. And it like helps them fight off infections."

Challenges for breastfeeding focused around a lack of support from the legal system (ex, if a mom has to go to jail), society in general and sometimes family members, and specifically that pumping is hard, and for some breastfeeding is painful and not fun. Dads also noted that anything the mom has (i.e. alcohol, tobacco, drugs, AIDS) passes to the baby.

Emotional- The emotional aspects of health and safety activities/behaviors included offering affection, praise and love to the baby (singing to them, skin-to-skin, carrying), and keeping baby active (story time, free resources, social time, etc.).

"I sing to her. I read books to her out loud. I point the pictures out to her. I show her the little things like that. I don't know, just telling her when the sun comes up."

Environment- As with Healthy and Safe Baby Concept discussions, the primary focus of comments was on environmental aspects including activities and behaviors to avoid around the baby such as alcohol or drunk driving, drugs, yelling, domestic violence, and "grown-up things" (TV, adult language). Also noted was not taking the party home, leaving your kids alone or hanging around with the wrong crowd.

Many participants also talked about teaching healthy behaviors by example and being healthy yourself so you can keep the baby healthy, as well as seeking support and resources when you need them.

"...getting help if they know if they're not able to handle – like being able to understand that if they're not prepared for something or – to ask for that help from somebody else."

SECTION 2: Health and Safety Activities and Behaviors

Breaking old cycles- A significant theme which emerged from discussions of activities and behaviors to keep babies healthy and safe was about the determination to break unhealthy family and community patterns and inter-generational cycles (ex, alcohol and tobacco use, teen pregnancy, violence) and create new patterns despite the pressures, lack of support or outdated information from family (ex, nutrition, safe sleep).

"I think we as native women have done such a good job...We're learning from our parents' mistakes or from our family's mistakes."

"My grandma tells me to do that. Lay the baby on their stomach."

"I was raised around smoke all the time, and I won't let it happen on her."

"I quit drinking. A lot of people in my family are alcoholics. And I told myself it's time to stop the wheel, the cycle going again."

"...it just goes on generation to generation, but then you think, well, I've got to stop this, and how am I going to change this? It's a fight."

Violence- Experiences of violence within the family or community evolved as a sub-theme and were shared in most of the discussions as a critical element in creating a safe and healthy environment for babies by both moms and dads; specifically the need to break the cycle. Creating a stable and safe home, being an example, recognition of the full impact of violence and different types of violence, and response to violence by the parents, family, community and society were all addressed. Moms noted that a lack of response to violence causes a lack of trust in support systems (ex, police, social workers, Child Protective Services and parents or other family). Participants also talked about wanting their babies to know who they are as native people as a way to give them strength against the cycle of violence.

"But lately as time goes on and there's more education that native women are getting the courage and they're getting the resources to be able to leave those homes and be able to say, "I don't want my baby born in this environment anymore."

"...with my daughter, I told her all of these things. I go, "This is what happened to me."

"I think before, like way back before, I think a lot of people were also getting away with it and not getting punished for it. And I think that really messes up a child too for letting the person that did it not get in trouble and think it's okay for the person to do it."

Traditional Practices- Comments on traditional practices spanned physical, emotional and environmental aspects, as well as spiritual and cultural aspects. Many practices defy distinct definition within the outlined aspects, but the categories are used loosely here to aid in outlining the information shared. Participants discussed 'teaching the baby that they are native' and 'keeping the native ways around them' as an activity/behavior to keep them healthy and safe; some related to physical aspects for the baby, such as dancing, time in nature, traditional/seasonal foods and creating and using cradleboards.

"I let her know that she's native and that's good to keep things alive."

SECTION 2: Health and Safety Activities and Behaviors

Others related to emotional aspects for the parents, such as blessings, singing, drumming, placenta/cord burial and other ceremonies such as sweats, prayer tie and sweet grass. Sage burning specifically was said to provide comfort in a sterile hospital environment. Environmental aspects included connection to the larger community, the Native American Church, learning through family/elders the old way, powwows and crafting and games with extended family and a community of women.

“Talk to your elders about babies, ask them questions.”

“I would think of ceremonies, because the babies being that little – they still can hear and feel. They can feel the parent, you know, going through something, or they can feel the parent or hear the parent singing, drumming. It will build memory.”

Participants also noted the need for native-specific educational resources and support, such as a native charter school (without the need for tribal registration), traditionally run childcare, a cultural center to teach crafts and other practices and activities that are open for all tribes because there are different practices for different tribes.

“...maybe that Indian community could start a child day care where they could learn their native ways... I would feel so much better taking her somewhere that was traditionally ran.”

SECTION 3: Barriers

Participants discussed barriers they experienced or perceived that prevented them from doing or avoiding the activities/behaviors mentioned above to keep their babies healthy and safe.

Lack of Support- Many comments were focused on the topic of support. Examples include finding and being able to trust sources of childcare, social isolation and lack of follow-up care from healthcare providers.

"I don't know what goes [on] once I walk out the door"

"I felt totally lonely. Like after I had my baby, yeah, I have my husband, I'm not single, but I still was like, I can't talk to my husband about that stuff. He don't want to hear my breasts are engorged."

"I just feel like, 'Okay, he's here.' Well the doctors aren't calling me. You feel kind of left out or, you know, 'Are they going to check and see how the baby is?' All the support is just like out the window..."

Conflicting Norms- Beyond lacking support, family and community norms which are unhealthy or outdated were seen as a barrier to doing what they know is right for their baby's health and safety; also addressed in discussions of Breaking Old Cycles. Specific examples included breastfeeding, smoking, alcohol and drug use around baby, nutrition, and car seat use (and specifically lack of car seat laws on some reservations).

"You see some people load up all their kids in a little truck, and they're like, 'All right, we're going to Wal-Mart everybody.' You just pack as many people as you can in."

While breastfeeding was supported for several moms, one facilitator offered the following insight about mixed messages for others: *"I think that they heard messages of breast feeding and the importance of breast feeding in the broader health care community, but in their own homes, their moms or mother-in-laws discouraged it. So they got both messages."*

Participants described being judged as outsiders and experiencing social pressure when making healthy choices for their babies; this issue arises again in discussions of Urban Life below. Participants also described feeling a lack of control over their baby's environment in settings outside their homes and especially for those who may be homeless, teen parents, or when staying with relatives, including when visiting family in the city or back on the reservation.

"It's so hard, especially when we go home because we're in their home, so sometimes you want to go visit your relatives. And so they're smokers. You can't ask them, "Hey, can you not smoke?" They're doing drugs... So the only thing you can do is like leave, but then yet there's tension there because they're like, "What, you're better than me?"

"I think just being around other people who do it; it's just easier to be lenient about breaking some rules that you know you probably shouldn't."

Lack of Resources- Both moms and dads said generally that lack of money and transportation among other general resources was a barrier; dads also specified job loss and unexpected bills.

"Transportation, especially if you have a lot of kids, getting back and forth to their appointments and stuff."

SECTION 3: Barriers

Stress, Teen parenting and Single parenting- Other examples of barriers incorporated all the above themes; these were stress, teen parenting and single parenting.

"Even though you may have people in your family, you might not want to tell them some things...Because what if they are the stress?"

"I think back now, and my family didn't really mentally support me. Here I am 15 years old, bringing this little baby home, and I was a single mom."

Maintaining Native Values- Dads described lack of cultural awareness, loss of native identity within the community and the challenge of maintaining native values in the "outside world" as barriers they perceived for AI/ANs in keeping their babies healthy and safe.

SECTION 4: Facilitators

When asked what makes it easy to do the activities and behaviors offered in a previous section to keep their babies' healthy and safe, one participant responded: *"It's not easy"*.

Resources, Support and Information- Many of the facilitators provided for keeping baby healthy and safe revolved around having resources, information and support. Urban Indian health organizations (UIHOs) and related services were described as a major resource; more detailed information on these discussions is in the Sources of Support and Sources of Information sections below. Other resource examples included transportation, healthy food, community resources (ex, Temporary Assistance for Needy Families (TANF)), Medicaid for teen parents and the free resources often received from UIHOs like baby-proofing tools and car seats.

Examples related to support and information included family and community coming together for the infant, classes, and support groups at UIHOs. Recommendations were made about the need for more parenting support groups, as well as access to information and healthcare resources in a consolidated place, such as at the UIHO, to make them the easiest to access.

Shared Norms- Other responses reflected a counter-point to barriers offered, like having control over their environment, setting an example by having a strong native identity and shared values among parents and other caregivers.

"...If I just set the example and I lay down the rules, and I'm pro-dominant crazy about it, then you won't have to worry about those things."

"I want them to know that they can be very strong, native women that can be very independent and not have to deal with that."

"I think it has a lot to do with the parents – things that you can agree on, things you talk about to make it easy to raise a child or things that are hard."

Traditions and Nature- Participants also provided examples such as traditional practices and ceremonies and spending time out in nature as facilitators to keeping babies healthy and safe.

"A lot of our traditional ways, bringing them [to the urban area] – we were raised really traditionally."

SECTION 5: Worries

Participants discussed what they worry most about and what they think other AI/ANs worry most about in trying to keep their babies healthy and safe. Many themes are grouped into contextual aspects.

Physical- Worries associated with physical aspects included communicable diseases (ex, pneumonia, Respiratory syncytial virus (RSV), whooping cough, and swine flu), risk for injury and questions about the safety of immunizations. Many participants also had concerns about hereditary illnesses causing vulnerability or manifesting later in life (ex, cancer, alcoholism, diabetes, mental illness).

"I think that she might hurt herself, because she's so active, and she wants to touch everything and get into everything... And one of my friends recently lost her baby – he put a little [item] in his mouth and choked on it."

"When they had a massive breakout of [RSV] here, my daughter was one of the kids that caught it. And she barely made it out of it, barely."

Sudden Infant Death Syndrome (SIDS)- Participants said that SIDS was a worry. They elaborated that they were constantly reminded of it and felt it was "in their face". Participants who had taken a cradleboard or other class at the UIHO knew about SIDS rates among AI/ANs, but others did not seem to know about the high rate of SIDS among AI/ANs. A handful of participants also remarked about a conflict with family norms around safe sleep.

"Everybody in my family said, 'Just put her to sleep on her stomach. That's how she likes to sleep. Don't worry about it... They change it every year.' And all this stuff. And I'm like well, this year they say on her back. And they say it all the time. So yeah. I'm afraid of it."

"I mean in the name itself, 'sudden' infant death, makes it – you know, sound like – oh my gosh. There's absolutely nothing I can do to avoid this. And if it happens, it just happens."

Emotional- Participants also offered worries related to emotional aspects of parenting, like being good enough and doing the right thing, the impact of separated/divorced families and single parenting, not having enough personal time, post-partum depression and experiencing racial/ethnic discrimination.

"Am I taking care of me properly enough to take care of her? I go through that one a lot."

"I think after you give birth and have a baby, you go through an emotional process where you have to get to know yourself again, you know, being a new mom and everything, you know, not to neglect yourself."

"What I worry about just day-to-day is am I doing a good job today with everything. Like am I yelling too much or am I not spending enough time, I'm not sitting down enough? It's a constant worry, though, if you're doing a good enough job."

Environment- As with other discussions, an unsafe environment was one of the primary worries of parents for keeping their babies healthy and safe. Specific examples included outside influences, lack of control (ex, in daycare or with Child Protective Services (CPS)) and drugs, alcohol, gangs and violence.

"The outside world; it's pretty rough out there. I have two kids, and they don't have a father. And I grew up without a father, so I know how it is out there. Alcoholism and drug abuse – it's big in my family. I

SECTION 5: Worries

had to cut most of my family off. And like she was saying CPS, you know, they're involved in my life. And just one mistake and my kids could be gone. So that's the fear."

Lack of resources- Worries related to lacking resources were common and spanned physical and environment aspects; including money, food, shelter, transportation, and access to healthcare and insurance and the lack of native-specific resources.

"I think money is one of the biggest issues because it seems like it's more expensive to make sure your child's eating healthy and around a healthy environment. I don't know why it is that way, but it is."

"And I worry about his diapers, like am I going to be able to provide him day care quick enough to find a job to afford diapers?"

"It's like sometimes you won't make it to the appointment if you don't have somebody to help you."

"I worry about her health. I don't know when she's going to get sick. I don't know if she's going to get hurt. The first thing I think about is – will she be okay? And then I think about – will her insurance cover it?"

SECTION 6: Sources of Information

Participants provided sources where they believe that AI/ANs receive most of their information on keeping babies healthy and safe; UIHO, other women and mothers, and family were the three most commonly cited sources by both moms and dads.

"I know a lot of native elders don't so much believe or agree with modern technology, modern medicine, modern methods and things like that. So that's why we get – they teach us that and then we reach out to places like Indian Health who give us more updated information [laughs]."

"I don't particularly rely on my doctor so much for baby information as I do [being] right here at the [UIHO]."

The following were also referenced by moms, listed here in order of frequency of mention: internet, doctors not associated with the UIHO, classes, books, and "The Happiest Baby on the Block" movie. Other specific sources included: childcare, public health nurse, social worker, and State or City online information networks (ex, 2-1-1 in Washington State). There were mixed opinions about the internet as a source of information on keeping babies healthy and safe.

"I would go to different forums that I could find to read what other women have went through in similar situations. And that was always helpful."

"For me the Internet leaves too much room for guessing."

Dads provided additional sources of information, including tribal leaders and the AI/AN community, community resources, counselors, church and school. Dads also mentioned brochures and commercials on specific healthcare issues (ex, asthma, and prematurity) after having babies with these diagnoses.

Trusted Sources of Information- When further prompted to suggest which sources they trust most for this information, UIHO staff then UIHO doctors were the most commonly listed; grandmothers and women with a lot of children were also mentioned. The idea that it, "depends on what it is" was also offered.

Trust yourself- An important sub-theme, several participants described their own instincts as one of the best information sources and offered a mother's intuition, the process of self discovery as a mom, and listening to what the doctor says, but then doing what feels right for your baby as examples.

"Trust your own instinct, because you know your child better than the doctor, better than anybody, so you would know, okay, hey, this is time to go to the hospital or this is time to call somebody."

Cultural Barriers- Many participants talked about barriers to accessing information from non-AI/AN doctors and hospitals. Specific issues and suggestions included impatience by doctors and staff, being seen as a number, health literacy, the need for cultural sensitivity training for providers, and a broader concept of wellness and values of strength and independence,

"...to have some sensitivity training for care providers if you're caring for native people, native communities...to have some sort of concept, a broader concept of wellness, that it's not just about your BMI. I'm so sick of hearing about that." [Laughs]

SECTION 6: Sources of Information

"My first doctor for my first baby...was not helpful. She was always impatient...I had to hurry up and get my questions out before she'd run out of the room. I got all my information in the waiting room from the parents' magazines... It was unenjoyable. [She left me sitting in the waiting room] for three hours one time. I was [pregnant]..."

"Sometimes when I go to the hospital they use a big word, and I don't understand it, and I have to ask them what it is. Last time they told me a viral infection, I thought she had an infection in her lungs or something. And it was just a cold, another word for a cold."

"It all goes along with how I'm going to raise my baby... If she gets sick, am I going to coddle her? Am I going to take her to the hospital every time she coughs or something? Just little things that doctors say you should bring your child in for, for me I don't think I should...If I got hurt, then just deal with it. If I was sick, you'll get over it...Indians, kind of walk it off."

Participants alternately described the experience of being known and cared about at the UIHO and similar cultural differences with nurses compared to doctors.

"Here [at the UIHO] I never had that problem, but anywhere I went before, they don't even [care] or know anything."

"...everybody here [at the UIHO] knows me..."

"[Doctors] kind of have to look at you as a number. Nurses are more like, 'Hey, how's your husband?' and they actually remember who your family members are. They're more involved with you personally."

SECTION 7: Sources of Support

Participants described sources of support for keeping baby healthy and safe, including family members as a primary source especially for childcare, WIC, and specific representatives like a Planned Parenthood Native American Outreach Coordinator for teen moms and online breastfeeding consultants. Traditional practices and ceremonies were also described as a source of support by moms; and some connected with the traditional practice of communal childrearing.

*"What about our ancestors, who had to use cloth diapers and they had to breastfeed, and they had to take care of a bunch of kids. How did they do it?
But like the women wrapped around each other.
It takes a village, too."*

"There's a little ceremony that the women do, so we got the placenta and buried it, and you say a prayer and stuff – you know, tribes do different things. It was kind of a lot. But it was nice to have this community of women."

UIHO- After family members, an overwhelming number of participants mentioned their UIHO as well as specific staff members as a critical source providing unique and valued support. Specific programs, services or benefits received at UIHO included Native Healthy Start, Fatherhood is Sacred, breastfeeding consultants, a teen mom program, free car seats and other safety tools, community health representatives, community events, connection to community resources and Medicaid.

"I like the groups here because we are alone at home and when I come here, this is the time I get to talk with other native moms and other mom's period."

"...not just the information that she shares, but how she presents it. Very professional. At the same time, she really cares...not condescending."

"I did it because [UIHO staff] took that time to put the flyer in my mailbox and send it to me twice..."

"What's great about the program here is that they let you know all of your options, but they don't influence what you choose. And they always support you. That's really great. Because your family won't do that, at least mine won't."

Home Visits- Participants elaborated on the benefits of home visits as a major source of support and educational materials and help with engaging dads and other caregivers in the home. Three of the four sites have home visiting programs.

"...having an unbiased not family member come in and help you out who just cares about you and your child and they're not trying to influence you and your personal beliefs."

"...because you can get caught up in whatever problem is going on, and then everything gets brought back to the kid and focus on the pregnancy and the children, and it reminds you of what's important."

"When she comes out, she does more than just, you know, helping. She did our medical papers, all that. And she sits there like a one-on-one counselor at times when, you know, we just vent to her and express what's going on... Somebody from the outside that doesn't play favors for anybody sit there and tell us what's going on."

SECTION 8: The Role for Men/Dads

Participants felt that AI/AN dads' role in keeping babies healthy and safe is a significant one. Both moms and dads described the responsibilities that they felt a dad should fulfill including generally being present, being a role model, being a provider, and offering characteristics that are unlike what the mom gives the baby. Moms and dads saw an opportunity with healthcare workers and especially home visitors to provide assistance in engaging dads and helping set expectations for dads to participate and be informed.

"I'd say for men, you know, so they could get that support for wanting to be in the family. You know what I mean? Some guys don't have support, and that's why they walk out. That's what I think."

Being present- This included spending time with and giving attention to the baby even when they are tired after work, loving and caring for the baby, and being more involved than they often are as parents by attending classes and groups, ensuring healthcare check-ups, and getting informed like the mom needs to be for the health and safety of the baby.

"I've heard a lot of men say that they were not sure how to participate, or how to be involved, or how to feel like they're part of what's going on."

"He [cooks] and he's a stock boy, so like I know he's tired, but when he comes home, he still plays with them, like gives them all of his attention when he comes home. I know he's tired."

Being a role model- This involved setting a good example (ex, healthy relationships with mom/women in general, how a man/dad is supposed to be, watching whom you bring around) and being a patient guide.

Being a provider- Providing financially for the family and home including taking care of the mom, and providing stability and protection especially for the pregnant mom.

Some differences seen between the dads' and the mom's role included having fun and playing more with the baby and also providing discipline as they get older. It was also mentioned that AI/AN men are traditionally ones that conduct select ceremonies.

"A native man right there is just conducting ceremonies or knowing what to do or who to ask to conduct the ceremony for you or just getting that part taken care of. Usually that's dominant when it's on the reservation and they're doing ceremonies is the man's usually the one."

SECTION 9: Communication Channels and Messages

Participants were asked to provide ideas for images, messages, materials, spokespeople and target audiences that would be most effective for reaching AI/ANs about keeping their babies healthy and safe.

Images- Similar themes were offered by moms and dads with regard to images, for example many participants noted the general absence of AI/ANs in mainstream media and felt that this in and of itself is a critical element of the proposed campaign.

“I see ads that have Spanish kids, or African Americans, but you don't see too much with Native Americans in there.”

Participants felt that it is important to represent varied physical characteristics and not just a traditional stereotype of AI/ANs. Images and messages should be multi-cultural to not exclude others and include mixed race families. It was suggested to show the entire family together, not just mom or dad or kids, and to show real people in the community and friendly faces.

Specific native images and components included: four colors/four directions, UIHO logos, flicker bands, the roundhouse, moccasins, bear claws, cradleboards, and to start with a drum and maybe singing to capture the attention of the AI/AN audience at the start.

More general suggestions included: bright and colorful rather than black and white images, “*more homelike, like family than at the hospital*”, and contemporary and professional images not necessarily traditional looking.

Messages- Participants offered suggestions for health and safety topic areas, as well as ways of delivering messages. In terms of topics, both moms and dads talked about safe driving/car seats and nutrition/eating natural unprocessed foods; while moms also discussed breastfeeding and dads spoke about alcohol use.

“I would say something to do with alcohol, because I think... a lot of us Native Americans, we have addictions, and that's a big thing.”

“[Tell them to,] Take the time [to use a car seat]. You know, it only takes a couple of minutes, not even that. You know, it's just a quick in and out.”

Regarding delivery, participants said the messages should be accessible, not intimidating for those who don't have a lot of support, “*Be nice about it.*” Also along these lines, some felt that scare tactics may be rejected, while many thought showing potential negative consequences of poor decisions would be effective. Dads specifically suggested showing the impact of lack of safety measures, use of car seats or drunk driving; like CPS, an injured baby, an impounded car or police action. Both moms and dads said that teaching by using positive examples from family and community should also be incorporated.

The quotes below further illustrate campaign messages suggested by moms:

*“...reinforce that **we know what we're doing. We've done it for centuries.** There's something really beautiful about the way we receive wellness in our communities and to incorporate that into an ad campaign that's multidimensional, that isn't just a brochure that you get from your doc on your way out, but that is reinforced at multiple levels.”*

SECTION 9: Communication Channels and Messages

"You see a lot of health-specific topics, like brochures and stuff like that. I think a good campaign that I haven't seen would be a whole-bodied campaign, so not just, 'Prevent SIDS in your child.' But something that promotes wellness in every stage, all sorts of ideas of wellness, **native concepts of wellness.**"

"...**stop that trend and look forward.** These are our [next] generation. One of the native kids could be the next president representing."

"...remind you that it is a community thing. That it does take a village, and **you're not by yourself, and you can ask for help,** and there aren't any stupid questions... and then having people like [UIHO Healthy Start Coordinator] to call when you need to, makes a huge difference. Especially for people who don't have other people to call. It makes a tremendous impact."

"it's just nice to know that **we're still there and people still care about our kids,** and just sending that message back they're our future, and we need to teach them some more."

Materials- Participants were asked about which options for campaign ad materials on keeping babies healthy and safe would work best in their area. A variety of responses were offered like, mail, TV, internet, posters, emails or text messages, billboards, bus ads, radio ads on the way to work, t-shirts, calendars with artistic, native images and recipes and other useful items such as baby proofing kits/gates, water bottles, and tote/diaper bags. Participants felt that magnets and key chains were nice as reminders about a program or event, but not for message delivery.

Additional discussions included TV, internet, email and direct mail communication avenues. Regarding TV, it was noted that digital video recorders have changed the viewing of commercials, as many people could skip them; similar comments were made about satellite radio stations. With regard to the internet, participants noted, "even the elderly use Facebook" and some watched videos on YouTube and suggested handing-out DVDs for free at AI/AN events. Participants felt that the information should come to them like in an email, rather than having to look for a website. Some moms enjoyed receiving weekly update emails about their babies and would be open to text format for this as well. Many moms suggested using direct mail; they stated they like to receive mail and sometimes feel less isolated when they did, although many also admitted to not reading materials received or ever connecting with services.

"I like [free stuff coming in the mail]...I've never even been out there one time, but they send me stuff all the time. And I feel like all – I have a partner or something."

When asked about previous ads, campaigns or other materials about keeping babies healthy and safe that caught their attention, examples most often provided were from TV or videos. Participants noted that a majority of ads they have seen were commercials for diapers, formula or other baby products, or car seat recalls, rather than health messages.

Participants also offered suggestions about locations where materials should be distributed. Dads' suggestions included casinos, gas stations, and liquor stores to target people who need information the most and moms offered UIHO, libraries, doctor's offices, grocery stores and toy stores.

Speakers- Participants were asked for examples of well-known or famous AI/AN people they look up to and think other AI/ANs would recognize and listen to for messages about keeping their babies healthy and safe. While a few potential speakers (both famous and not) were offered in each area, mostly

SECTION 9: Communication Channels and Messages

participants felt that people whom were known and trusted in each community, like staff from the UIHO or elders, and not necessarily a famous person, would be most effective.

"I think it should be focused less on Hollywood actors. It would have to be a regular woman like all of us, yeah."

"A real woman with a real life."

Target audience- Participants were asked who the campaign ads should target specifically and why; prompts suggested options such as youth, moms, pregnant women, doctors or other healthcare staff, politicians, and men. A majority of participants felt that the target audience should be “everybody”, and some felt that pregnant women, parents and youth should be targeted because, “*They're right there with the baby*”. Participants remembered selected ads where a positive image of AI/ANs was shown to a wide audience in the larger population, which provided a sense of pride. Many also talked about the importance of targeting specific ads for different areas.

"I would say 'all', because the politicians and the doctors and the staff have the say-so and they can put it up to be voted on and get it for us. And then we are – like the moms and the youth and the men, we're going to gain from it all, and keeping the baby and children safe."

"If you're just targeting moms, then the burden is all on moms to create a healthy environment for a baby."

"They put it on a station where they know that other cultures will hear it. It kind of gave me like a sense of pride to natives... 'Cause some people kind of look at natives as just being drunks, asking for money at the bus stops or things like that. I don't know. Sometimes Indians don't really have a good reputation for being individuals. But I thought that was really cool that... everyone could hear... We're a proud people..."

"If they want to target Native Americans, maybe if it is on a reservation or urban areas, target the specific groups like they have specific ads for specific people to live in, in specific areas."

SECTION 10: Suggestions

Participants were asked about suggestions for better ways to inform and support AI/AN parents in keeping their babies healthy and safe.

Support Groups and Activities- Participants suggested the need for a greater variety of fun activities to provide support for keeping babies healthy and safe. Ideas included a clothing exchange, play dates, family pot lucks; programs and support groups for new mothers, post-partum depression, and alcohol/drug use; training of youth about childbirth and after, car seat training and a series of Q and A sessions on different topics. Dads felt grateful for the “Fatherhood is Sacred” program in Sacramento and thought others should also have this resource.

Also suggested were groups for the whole family inclusive of small children and babies, which may be addressed with provision of childcare, consideration of challenges around work and seasonal schedules, keep activities free, provide food and childcare, and hand-out free safety supplies.

"Some of them we'd like to attend, but some of them don't allow younger kids in it. So that's – you know, kind of get cut off right there, especially when you don't have nobody to watch them."

"One parent works during the day, and the other parent works in the evening. I guess time schedule is just the main, biggest part. And then weekends, I know we always either go to a powwow or go somewhere. We're hardly home, especially spring and summer coming up."

"Take a whole day just devoted to car seats and babies and safe driving and buckling up."

One group discussed the idea of a phone tree support system to address isolation of new moms and to build community.

"...something for other mothers, like a phone chain kind of a thing, like, "Oh yeah, this person's in my group. Let me call them and see if they have any insight or just to talk or you feel alone."

"Well yeah, some people just need someone to talk to. If you can't see them physically, you need someone to let out all your frustrations."

"Aunties for your kids"

Outreach to AI/AN- Dads suggested reaching out to AI/ANs who are not already connected to the community by distributing information about programs and events at non-AI/AN specific locations like private healthcare and hospitals.

Cultural Awareness- Participants described the need for awareness of AI/ANs in urban areas and cultural diversity training; especially among care providers.

"I've heard people say oh; I didn't even know there were natives in Detroit. You know? I think that awareness and cultural diversity need to go right hand in hand. And community effort."

"I think a lot of health care workers – a lot of daycare centers and preschools and stuff like that definitely need more– you know, cultural diversity training"

SECTION 11: Urban Life and UIHO

The themes below were not intentionally prompted in discussion questions, but emerged as distinct and important to participants' experience of keeping their babies healthy and safe.

Urban life- Participants described issues unique to life for AI/ANs in an urban setting, including benefits, and challenges compared to life on a reservation or other settings, and also suggestions for ways to improve the health of the community.

Benefits: Participants felt that the urban setting provides more resources, more options and activities (ex, powwow class or cub scouts), a better legal system, and more jobs. Participants also described how the urban environment offers a new perspective on unhealthy patterns, acceptance of new norms for health, as well as less judgment of racial/ethnic/tribally mixed families, because of reduced social pressure compared to life on reservation. Participants felt that dads are often more involved with the baby in urban areas than on reservation because of the need to survive (i.e. both parents working) and that parents in general are more affectionate; both of these were also attributed to less negative social pressure in urban areas.

Challenges: Challenges of urban life in general and for keeping babies healthy and safe included the lack of awareness by the larger population of natives living in city and negative stereotypes, perceived and real limitations accessing native-specific resources without Tribal registration, difficulties maintaining knowledge of native traditions, challenges connecting to community because of being new to the area and having to create a life from scratch (ex, job, home, car, church, social and family life), having neighbors complain about the smell from the traditional practice of burning sage, and fear of the dangers in the city (ex, drugs, school shootings, violence).

"I know a lot of mothers or pregnant women and even men who really want to get involved in services but think that they are strictly excluded for one reason or another. A lot of people say, "Oh, I don't have a tribal registration card. There's no way I can be involved."

"I know a lot of people who get frustrated looking for services and also sometimes they get intimidated."

"It goes back to the whole trauma thing. Because like my dad's brothers are stronger native. But my dad got away from it. He was also in boarding schools. So when he came up here from up north, from Arizona, he didn't take all that culture with him. I had to kind of find it out myself."

"Here in the city, we have to survive."

Participants also described challenges related to native identity such as not being recognized as native because of physical and geographic stereotypes, and judgment of racial/ethnic/tribally mixed families from family or community on the reservation.

"It's amazing how many people don't even know just how great of a population we have here in the city. I've had people tell me I didn't know there were natives in [the city]."

SECTION 11: Urban Life and UIHO

Suggestions for these challenges included; resources should be open to everyone and events and information should reflect many tribes and areas, and the need to teach acceptance of other tribes, and mixing tribes/races/ethnicities in a family. Participants felt hopeful about the possibility of changing the negative stereotypes of the larger population.

"It's okay to be half and it's okay to live in an urban area and still feel like a native 'cause a lot of us are making lives for ourselves out here; it's hard. We have to work 20 times harder, you know?"

"We're so different from people on the reservation. I didn't marry a Native American man, so my kids don't look native. So when they go home, they're always teased. So I think the emotional part is important to show that's okay to date a non-native man or it's okay for a man to date a non-native woman, to incorporate that because we are in an urban environment, and you're going to be exposed to – we're going to be the minority of course. And we're going to have to learn to assimilate into another race. And it has nothing to do with losing your culture; that's up to us. If we want to lose our culture, we're going to lose it."

"I think that would kind of help a lot of natives too is just letting them know that it's okay to live in an urban area and being a Native American and get a good education and be very healthy."

UIHO- Beyond specific programs or services provided at UIHO, participants made comments about the irreplaceable sense of community and place that they feel at UIHO.

"[It's better for those that don't have families] to come to places like this. It's really important, I think, to keep programs like this going."

"We benefit in a lot of ways. But we don't have anywhere else that we go for stuff like this."

"They should just skip the whole ad campaign and put all the money into [Native] Healthy Start programs. Putting them everywhere... They should make it a nationwide service."

"I think that going to the [UIHO] is the only thing that's keeping me well, because every time I go there, they keep me stimulated..."

"It's small, what we have here. But it's – the quality's good."

Summary

Campaigns with previously developed materials are often adapted to include AI/AN images or symbols, but formative research to learn about the target community, effective messages and communication channels to best reach AI/ANs 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. The findings from discussions with urban AI/AN parents described above will be used to develop materials for a communications campaign to increase awareness of infant mortality and help improve the health and safety of AI/AN babies in urban areas. These materials will be shared with the participating sites and communities, and recommendations will be made for the up-scaling of the campaign to the nationwide urban AI/AN audience, as well as the broader AI/AN population.

References

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Appendix A: Additional Survey Findings

The findings below were collected by anonymous survey from all focus group and interview participants. Socio-demographic data from the survey is provided in the Findings section of the report in Table I.

Insurance- Participants were asked if they had health insurance and if so, which type(s). A majority of respondents from three sites that provide primary health care services reported having health insurance (N=25, 93%), while only two (22%) respondents from the referral site in Salt Lake City reported having health insurance. Specific sources of insurance reported in order of frequency (in parentheses) were: Medicaid (8), Medi-Cal (6), Medicare (5), Blue Cross/Blue Shield (3), SSI/SDDI (2), private insurance (2), Department of Social and Health Services (2), and Group Health (2).

Healthcare Source- Participants were asked to identify where their family receives most of their health care. The Indian Walk-In Center in Salt Lake City, UT does not provide direct primary care; therefore respondent data from this site was analyzed separately. Sixty-seven percent (N=6) reported using a Community Health Center and 33% (N=3) still reported the Indian Walk-In Center as their source.

Healthcare source	Number (%) (N= 27)
Urban Indian health organization— Detroit, Sacramento, Seattle	12 (40%)
Community Health Center	3 (10%)
Private Health Clinic	5 (17%)
Indian Health Service Facility	5 (17%)
Other	4 (13%)
Hospital	1 (3%)

Percentages based on number of responses in each category; variances are due to rounding
“Decline to answer” and “Don’t know” responses are excluded from table

Tribe- Participants were asked if they were enrolled in a tribe and to list their tribal affiliations. A total of 30 tribal affiliations were identified and most respondents were enrolled in these tribes.

Site	Tribes
Detroit	Aztec, Blackfoot, Cherokee, Chippewa, the Little Traverse Bay Band of Odawa Indians, Oneida (2), Sault Chippewa, and Seneca
Sacramento	Coast Miwok, Gila River Pima, Miwok, Pit River-Chippewa, Pomo, Sioux (2), Tohono O’odham, and Yurok
Salt Lake City	Chippewa Cree (2), Crow, Hopi, Kiowa, Navajo (3), Skull Valley Band of Goshutes (2), and White Mountain Apache
Seattle	Assiniboine Sioux, Blackfoot, Cherokee, Choctaw, Inupiaq, Klamath, Lummi, Northern Cheyenne, and Sioux Dakota

Multiple respondents listing a tribe shown in parentheses

Counties- Respondents provided their zip codes, which we used to estimate the counties they reside in.

Site	Counties
Detroit	Macomb (1), Oakland (1), and Wayne (6)
Sacramento	Sacramento (12)
Salt Lake City	Salt Lake (9)
Seattle	King (6), Snohomish (1)

Source: <http://quickfacts.census.gov/cgi-bin/qfd/lookup5>

Number of respondents shown in parentheses

Media & Information Sources- Participants were asked if they and their family regularly use a TV, DVD player, computer with internet access and/or a DSL or cable modem; they checked each source they regularly use. Additionally, they were asked to identify where they received information on health related issues. Participants checked each category where they received information.

Information Sources	Number (%) (N= 39)
<i>Media Access and Use</i>	
Television	35 (90%)
DVD player	26 (67%)
Computer with internet access	13 (33%)
DSL or cable modem	7 (18%)
<i>News and Information</i>	
Health care providers	24 (62%)
Family members	23 (59%)
Friends	17 (44%)
Community groups/organizations	14 (36%)
Internet	13 (33%)
Television	10 (26%)
Newspapers	4 (10%)
Radio	2 (5%)
Schools	3 (8%)
Church	2 (5%)
Other sources	2 (5%)

