American Indian Infant Mortality Review Project

Minnesota
2005-2007

Summer 2008

Maternal and Child Health Section
Community and Family Health Division
Office of Minority and Multicultural Health
Center for Health Statistics
Office of Public Health Practice

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The American Indian Infant Mortality Review Project 2005-2007

Table of Contents

Acknowledgments

Many partners made this project meaningful and useful for the future work of community programs and health care services for American Indian women and men and their families and, most especially, for their babies. The Minnesota Department of Health is deeply grateful for their service.

All members of the project sincerely thank the mothers and other family members who took the time to participate in the interviews and share their experiences, feelings and advice. You have made an important contribution to prevent future American Indian infant deaths.

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Executive Summary

Minnesota's American Indian population has a longstanding disparity in infant mortality rates as compared to the White population. As reported by the Minnesota Department of Health's Center for Health Statistics, the American Indian infant mortality rate in Minnesota for the years 1989-1993 was 16.2 per 1,000 live births while the rate for the White population was 6.5 per 1,000 births. In 2000-2004, the American Indian rate was 10.2 deaths per 1,000 births as compared to the White rate of 4.5. While both populations made improvements in infant mortality rates, the disparity between the groups remains nearly the same.

The Minnesota American Indian Infant Mortality Review Project was undertaken to address concerns about the infant mortality disparity and was designed to meet the following objectives:

1. Gain new insight into medical, social, and environmental factors that contribute to infant mortality.
2. Develop recommendations for improving systems of care and services provided during pregnancy and infancy.
3. Disseminate and implement recommendations.

Partnering with the Minnesota Department of Health (MDH) in this project were tribal and urban Indian community agencies, the Great Lakes Inter-Tribal Epidemiology Center, and the Bemidji Area Office of the Indian Health Service.

This report documents the process and findings of the Infant Mortality Review, and includes the complete list of recommendations generated by the Case Review Team. The next steps in this process will be to review and refine the recommendations, then develop and implement actionable strategies that will reduce the number of infant deaths within Minnesota's American Indian community.

Summary of Findings:
Thirty-one American Indian infant deaths occurred in 2005 and 2006, and of the 31 deaths identified, 24 were reviewed. A version of the National Fetal and Infant Mortality Review process that included a maternal interview, assessment of vital records, and abstraction of medical records was used in conducting the review. A multidisciplinary panel discussed each case, identified contributing factors, and developed recommendations to reduce future deaths.

In the study group, the leading causes of infant death were Sudden Infant Death Syndrome (SIDS) and sleep-related unintentional injury. Other causes of death included complications of prematurity and birth defects. Most American Indian babies died in the post neonatal period (from 28 days to one year of age) unlike the population of Minnesota infants overall, most of whom die in the neonatal period (birth through 27 days).

Factors contributing to the deaths included receiving late and inadequate prenatal care, use

of substances during pregnancy, and infants placed in unsafe sleep environments. All of these factors are potentially modifiable with public health education and an investment in prevention resources.

Following are highlights from the complete list of recommendations developed by the Case Review Team and included in this report.

Highlights of Recommendations

- Include fathers in all parent education.
- Prioritize education and resources to assure safe infant sleep practices.
- Develop public service announcements for American Indian communities on infant mortality risk factors.
- Strengthen the community norm for early and adequate prenatal care.
- Make early and regular prenatal care more available and accessible.
- Assess and address substance use at every prenatal visit.
- Review protocols for high risk perinatal triage and transfer.
- Provide and promote preconception and interconceptional care, including family planning.
- Increase culturally specific approaches and resources to reduce use of substances for women of childbearing age.
- Increase funding for teen pregnancy prevention.
- Assure that substance abuse prevention and treatment, for recovering mothers and their children, is available and includes supportive housing.
- Address cultural sensitivity and racism.
- Develop culturally specific grief support services.
- Assure ongoing infant mortality review in Minnesota.

THE AMERICAN INDIAN INFANT MORTALITY REVIEW PROJECT 2005-2007

Introduction

The purpose of the American Indian Infant Mortality Review Project is to respond to community and professional concerns regarding the high infant mortality rate within Minnesota's American Indian population. Through the review process, contributing factors that impacted infant deaths were identified and recommendations developed to address the identified contributing factors. American Indian leaders, in partnership with Minnesota Department of Health (MDH) staff, plan to work together to develop strategies and implement changes that will reduce infant deaths.

This report describes the process, findings and recommendations from the 2007 review of Minnesota's American Indian infant deaths that occurred in 2005 and 2006. It is written to inform American Indian community leaders, MDH program staff, and other interested persons and organizations about what was learned during the review, and to share recommendations to reduce American Indian infant deaths.

Background

Minnesota has one of the lowest infant mortality rates in the nation. Yet, in Minnesota's American Indian population babies die at a rate two to three times higher than in the White population. This disparity in infant mortality rates has existed for more than 20 years, as long as infant mortality rates have been calculated by race and ethnicity by the MDH's Center for Health Statistics. Although the total number of infant deaths has been reduced in Minnesota during the last two decades, the size of the gap between White and American Indian babies persists.

This disparity in infant mortality rates has been of longstanding concern to many. In 2005, public health officials at the tribal level, urban Indian agency representatives on the Maternal and Child Health Advisory Task Force, and the Mothers and Infants Action Team (MIAT) in northwest Minnesota raised these concerns with MDH staff. In response, the Commissioner of Health, in 2006, allocated $20,000 of state funds for the purpose of reviewing American Indian infant deaths. The Infant Mortality Review (IMR) process was suggested by tribal nursing directors and recommended by MIAT.

What is Infant Mortality Review?

Fetal and Infant Mortality Review (FIMR) is a methodology promoted by the National Fetal – Infant Mortality Review (NFIMR) program, a program created by a partnership between the American College of Obstetricians and Gynecologists and the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services. FIMR evolved as a public health strategy nationally in the mid- to late 1980s as a promising method to improve local factors contributing to fetal and infant mortality and to motivate community response. The MCHB has encouraged state public health agencies to

institutionalize FIMR as an integral component of core public health functions.[1] Minnesota has sometimes prioritized infant mortality review (IMR) over FIMR when resources were not sufficient to review all deaths. In this project, reviewing infant deaths was the priority given the available resources.

IMR brings together a wide variety of people to improve understanding about the causes of disparities in infant mortality, with an underlying and primary goal of identifying necessary system and community changes. Ideally, IMR is to be conducted at the community level and serve as a continuous quality improvement process. Case summaries are developed for each death occurring within the time frame and population identified.

The Minnesota Process

The Minnesota IMR project targeted all American Indian infant deaths in the state of Minnesota that occurred within the first year of life during the years 2005 and 2006. Information for the case summaries was obtained from birth and death records, health care records, autopsy reports as well as interviews with individual mothers (when available) and one grandmother. Qualitative and quantitative data were combined to create a comprehensive picture of each infant death. Confidentiality was assured for families and health care providers. Upon completion, an expert panel, representing a cross section of professionals and community people, reviewed each case summary.

MCH staff began the process of creating an internal steering committee (ISC) and obtaining Institutional Review Board (IRB) approval as soon as funding was secured. In November 2006, the proposed project was presented to Tribal Health Directors.

Internal Steering Committee (ISC)

The Internal Steering Committee included the following MDH staff: the Urban Indian Health Coordinator and Tribal Health Liaison from the Office of Minority and Multicultural Health (OMMH); two research scientists, one from MCH and one from the Center for Health Statistics; the district nurse consultant from Duluth; and three MCH staff, including the infant mortality consultant, the family home visiting consultant to the tribes, and the supervisor of the Family and Women's Health Unit. The infant mortality consultant served as the project coordinator because of her prior experience in coordinating infant mortality review projects.

In January 2007, the ISC sent letters to previously identified American Indian people across the state (including tribal chairs, health directors and key organizations such as the Bemidji Area Indian Health Service) notifying them of the project and inviting their participation on the Case Review Team (Appendix A, letters).

Institutional Review Board (IRB)

An application outlining the proposed project was submitted to the Institutional Review Board at the Minnesota Department of Health. The project received approval in February 2007. (The purpose of the IRB is to protect vulnerable populations from harm that could potentially result from participation in a research study.) In mid-March, the ISC learned

that this project would also require Indian Health Service (IHS) approval, which was subsequently received from the national IRB of the IHS in May 2007 (Appendix A).

Death Selection and Data Sources

Deaths of Minnesota resident infants up to age one year, where either of the parents or the child at death was identified on the vital records as American Indian, including those of mixed race, were included in the study. Birth and death records for years 2005 and 2006 were reviewed and thirty-one deaths meeting these criteria were identified.

Additional data sources examined included medical records, autopsy reports, and when possible an interview with the mother of the infant.

Maternal Interview

The interview tool used in Minnesota's infant mortality review projects in the late 1990s, was reviewed and revised, making it shorter and more culturally specific to the American Indian community (Appendix B, interview). The interview tool included open-ended questions that the interviewer could tape record (with permission) and 114 short-answer questions.

Maternal interviews were conducted by American Indian interviewers who were from the geographic area where the mothers lived. Maternal interviewers were required to attend a training session. Of the five contracted interviewers, four interviewers were public health nurses and one was a social worker. The training agenda for the maternal interviewers (Appendix B) included an overview of the interview process including obtaining informed consent and release of medical records from the mother, interviewers' responsibilities as mandated reporters in the event child maltreatment was identified, identifying and responding to unresolved grief or other family issues and needs, use of incentives, and use of the interview tool itself. All maternal interviewers were required to sign a confidentiality agreement (Appendix C, consents).

Incentives

An incentive for participation was provided due to the interview's length. Each mother interviewed received a $50 gift card at the time of the interview and an additional $50 gift card was sent to her after the interview.

Consent to Participate and Release of Medical Records

Mothers were notified of the project by letter (Appendix A). Then an interviewer visited each mother to explain the purpose of the project. The interviewer obtained the mother's signature on the "Informed Consent to Participate" form and on a "Release of Medical Information" form (Appendix C). The interviewer explained that these documents and the interview would be summarized without identifying information for the case review process.

Upon completion of the interview, the project coordinator provided the release of medical records to an abstractor under contract with the MDH. The abstractor had prior experience abstracting medical records for infant mortality review projects in Minnesota. The abstrac-

tor was required to sign a confidentiality agreement specific to medical records abstraction (Appendix C).

Case Review Team (CRT)

A Case Review Team of 20 persons met for an orientation in March 2007. They were invited to participate by the Internal Steering Committee because of their knowledge of and experience with the American Indian community and their expertise in maternal and infant health. The orientation included a presentation on the goals and purpose of the project as well as a history of infant mortality. All CRT members were required to sign a confidentiality agreement (Appendix C). Two members were selected by the team to be co-chairs, one from the metro area and one from greater Minnesota. The team met again in June 2007, after IHS IRB approval was obtained and cases had been prepared for review.

Case Summaries

All information from vital records, medical records and maternal interview data that might identify the family, provider(s) or hospital(s) was removed from case summaries by the project coordinator and summary writer. Cases were summarized in a concise narrative for the CRT. The summary writer worked under contract for the MDH and was required to sign a confidentiality agreement (Appendix C).

Review Process

The CRT met four times between June and October at the Mille Lacs Reservation in Onamia, Minnesota. This venue was centrally located to reduce travel time for CRT members. Eleven deaths received a full review and an additional 13 deaths were partially reviewed based on available information. Attendance at review meetings ranged from 12 to 22 persons. Each case was discussed using a format that helped CRT members identify contributing factors and develop recommendations (Appendix D, worksheet). At the final meeting, all recommendations were compiled for further review and editing by the CRT and overarching recommendations were developed. The co-chair further revised and organized recommendations and distributed them by e-mail to all CRT members and to the ISC for comments.

Findings

Eleven mothers and one grandmother of the 31 American Indian infants that died in 2005 and 2006 were interviewed. Of the 19 remaining cases, one mother moved out of state and 12 were not located for interviews. Partial reviews, including review of vital records and autopsy reports, were completed on six of the 12 cases not located for maternal interviews. These cases involved apparently healthy infants who died of a sleep-related cause. The Internal Steering Committee determined that a partial review of these six cases would provide an opportunity for the CRT to discuss this particular cause of death.

Five mothers were not asked for an interview because their tribal council decided that they had been traumatized enough by their baby's death and did not want them to be approached. These five cases received a partial review based on vital records and available autopsy reports.

One mother was not approached for an interview because the case was a homicide. The CRT decided to review the case to determine whether systems issues may have contributed to this outcome. The review was based on vital records, autopsy report and the homicide detective's report.

Findings are reported on the 12 cases that included an interview. Partial findings are reported on the 12 additional cases reviewed without an interview. Consequently, some findings reported are based on the 12 interviewed cases while other findings are based on the 24 cases reviewed. (See Figure 1, Guide to Case Review Sources)

Figure 1: Guide to Case Review Sources

Group A	
11 mothers interviewed	CRT review of summarized interview, vital records, and available medical records and autopsy reports
1 grandmother interviewed (mother missed scheduled appointment)	CRT review of summarized interview and vital records
Group B	
6 sleep-related cases (mothers refused interview or were not found)	CRT review of vital records and autopsy reports
Group C	
6 other cases (mothers not approached for interview)	CRT review of vital records and available autopsy reports
Group D	
7 cases (mothers refused interview or were not found) [See Appendix F]	vital records reviewed by project staff only

Demographics and Other Descriptive Information

Metro/Greater Minnesota: Because the total American Indian population is small and infant deaths are rare, geographic identification was limited to "metro" and "greater Minnesota" to protect identification of individual cases. Of the 24 reviewed deaths, 13 mothers were from the metro area and 11 were from greater Minnesota.

Race/Ethnicity: Of the 11 mothers and one grandmother interviewed, 10 mothers were American Indian and two were White. Seven fathers were American Indian, two were Latino, two were White and one was unknown.

Of the 12 cases reviewed without maternal interviews, vital records data indicate 11 mothers were American Indian and one was White. Nine fathers were not identified on the birth certificate; two fathers were identified as American Indian, and one as Latino.

Age: Ages of the 12 mothers where an interview was conducted ranged from 15 to 36. The 12 mothers whose cases were reviewed without an interview ranged in age from 17 to 34. In the 24 reviewed cases, six of the mothers were under age 20. Three were 19 and one each was 15, 16 and 17 years of age.

Fathers' ages were reported for 11 of the 12 infants for which an interview occurred and ranged from 17 to 41 years of age. Seven fathers were in their 20s.

Education: Of the women interviewed, mothers' education levels ranged from sixth grade to college graduate. Three mothers were high school graduates, five had college educations and four had not completed high school. Two of those four were under 20 (15 and 19) and two were in their twenties.

According to birth records, education levels of the 12 mothers not interviewed were as follows: one had a college education, six were high school graduates, and five had not completed high school. Of those five, three were under 20 (16, 17 and 19) and two were in their twenties.

Tobacco: Of the women interviewed, it was reported that eight of the 12 mothers were smokers (67%); two said they quit smoking during the pregnancy. One of the non-smokers said she was regularly exposed to secondhand smoke.

Of the 12 mothers whose infant deaths were reviewed without a maternal interview, vital records data indicated that three of them smoked during pregnancy.

Overall, 46 percent (11 of 24) of the mothers smoked. By comparison, vital records data indicated rates of smoking during pregnancy among American Indian women for Minnesota as a whole averaged 38 percent during the period 2002-2006.[2]

Alcohol and Drugs: Of those interviewed, five of the mothers used drugs during pregnancy that included crack cocaine (1), marijuana (3), and methamphetamine (2). One mother said she quit methamphetamine when she found out she was pregnant. Eight mothers used alcohol; six of them reported that they quit drinking when they found out they were pregnant.

Of the 12 mothers whose infant deaths were reviewed without an interview, vital records data indicated one mother used marijuana (six of 24 mothers used drugs, 25%). Vital records did not indicate that any of those mothers used other drugs or alcohol. It is very important to note that vital records underreport risk factors such as use of alcohol, tobacco, or drugs during pregnancy. The maternal interview is considered a more reliable source of chemical use.

Prenatal Care: "Inadequate prenatal care" is a measurement of quantity, not quality of care. In general, it is defined as care that begins later than the first trimester and the number of visits is not appropriate to the length of the pregnancy.

Seven of the 11 mothers interviewed began prenatal care in the first trimester and had sufficient visits (58%). Four began prenatal care in the second trimester. Of the four who had delayed care until the 2nd trimester, one had trouble getting an appointment as early as she wanted and had difficulty getting time off work. Another mother also stated that getting time off work was a barrier to getting early care. A third mother listed having to wait four

to six weeks for an appointment and having trouble getting time off work as barriers to receiving early and regular prenatal care. The fourth mother was too busy at work and had too many other things going on affecting her ability to access early prenatal care.

Eight of the 12 mothers who were not interviewed had inadequate prenatal care according to birth record data. They either started care later than the first trimester or did not have the appropriate number of visits according to the length or gestation of their pregnancy.

In this project, 11 of 24 mothers (46%) had early and adequate prenatal care. Based on vital records, Minnesota's overall rate of early and adequate care for American Indian women was 51 percent for 2001-2005. The rate of early and adequate prenatal care was 82 percent for Minnesota's White population during 2001-2005.[3]

Birth Weight and Gestational Age: Infants are considered born at low birth weight (LBW) if they weigh less than 2500 grams (5 lbs. 8 oz.). They are considered preterm or premature if they are born before 37 weeks gestation. Being born preterm and/or at LBW is a major risk factor for infant death, especially death in the first month of life (e.g. the neonatal period).

For the 24 cases reviewed, vital records indicated that 13 babies were born full term, 12 at a normal birth weight and one at a high birth weight (over 4000 grams or 8 lbs. 13 oz.). One baby was born post term (42 weeks gestation) at high birth weight.

One baby was of normal birth weight but born preterm at 35 weeks gestation. Nine additional babies were born preterm and LBW. Five of the nine (21%) were extremely preterm (20-23 weeks gestation) and extremely LBW (slightly under or over one pound).

For the total 24 deaths, 10 infants were preterm (42%) and nine were LBW (38%). (See Figure 2, Birthweights of American Indian Infants Reviewed)

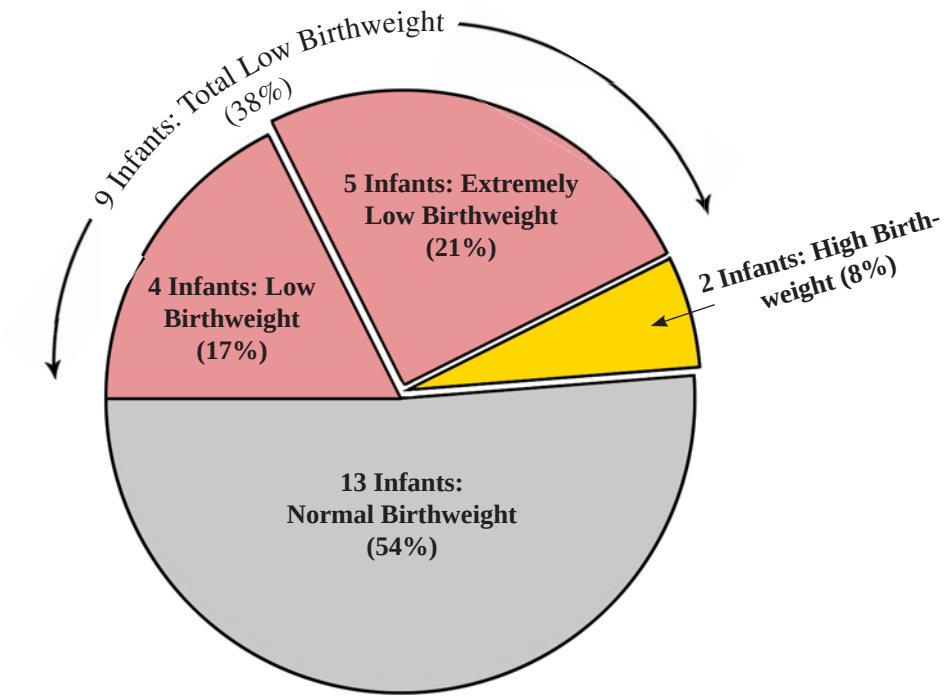
Additional Socioeconomic Information

The following descriptive information came from the 12 cases with an interview. This type of information is not available on vital records so it could not be determined for the cases reviewed without an interview.

Income, Employment, and Insurance: Income ranged from $0 to $35,000 per year for households that varied from two to seven people. Eight women were on the WIC Program and were considered low to moderate income. Eight had their health care covered by Medical Assistance. Three had health insurance from their employers. Nine women worked during pregnancy, one was a high school student, one was supported by the baby's father and one mother was reported to be without a regular source of income. Overall, the mothers had low to moderate income.

Social Factors and Other Living Conditions: Six mothers rented their homes or apartments and lived with the father of their baby. One rented and lived with a friend and her children. Two couples owned their homes. Two mothers lived with their parents. One mother was homeless.

Figure 2: Birthweights of American Indian Infant Deaths Reviewed, 2005-2006 (N=24)



Work Conditions: Of the nine working mothers, three reported that their working conditions were stressful. The other six mothers were in jobs that they did not believe were stressful.

Social Supports: All eleven of the mothers interviewed described a support system available to them that included husbands, boyfriends, mothers, sisters, other family, friends, and spiritual support.

Stress and Depression: Five of the 11 mothers interviewed and the grandmother described stressful situations in the mothers' lives besides the death of their baby. Stressful conditions existed in either work situations or at home with family relationships. Two of the 12 mothers were treated and monitored for depression during pregnancy. All reported that they were sad at the time of their infant's death. Four of the 12 received counseling at that time and eight mothers did not. The interviewers referred two additional mothers for counseling.

Weight for Height: Six of the 12 mothers were overweight before pregnancy by body mass index and six were of normal weight for height.

Mothers' Perception of Care: Seven of the 11 mothers interviewed were satisfied with the care they received from the health care system. Four mothers and the grandmother (42%) were not satisfied with the care at the delivery hospitals. Complaints included poor communication and insensitive remarks. Two mothers felt the quality of their hospital care was poor.

Causes of Infant Deaths

Neonatal deaths are those that occur in the first 27 days of life. Post neonatal deaths occur from 28 days to one year. Of the 24 deaths, six neonatal deaths (25%) and 18 post neonatal deaths (75%) were identified in this study. Three-quarters (75%) of the babies died during the post neonatal period. One-quarter (25%) died during the neonatal period. This is in contrast to the overall population in Minnesota where nearly two-thirds (64%) of infant deaths occurred in the neonatal period and just over one third (36%) in the post neonatal period.[4]

Half of the deaths reviewed (12 of the 24) occurred to babies who were born apparently healthy and died during the post neonatal period from sleep-related causes.

Sleep-related Causes

Sleep-related causes include both Sudden Infant Death Syndrome (SIDS) and sleep-related unintentional injuries. SIDS is considered a death that is not preventable, although there are many things parents and caregivers can do to reduce the risk of SIDS. Some of the most important risk reduction practices are to always have babies sleep on their backs, never expose babies to tobacco smoke either during pregnancy or after birth, and to provide a sleep environment that is designed with infant safety in mind. The definition of SIDS is:

> The sudden death of an infant under one year of age, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.[5]

Sleep-related unintentional injury deaths are less well-defined than SIDS. Causes of these deaths may be called positional asphyxia, suffocation, entrapment in furniture or bedding, overlay by another person, occlusion of external airway, and sometimes “undetermined”. The differentiating feature of these deaths from SIDS is that they are considered preventable if parents provide a sleep environment that is safe and use it consistently for all the baby’s sleep periods.

Of the 24 deaths reviewed, 12 babies died of sleep-related causes: three from SIDS (13%) and nine from sleep-related unintentional injury (38%). The cause of death for five of the nine was asphyxia, four were “undetermined” but with unsafe sleep environment noted as contributing to the death.

Prematurity

Five of the 24 babies died of prematurity (21%). Four of the five babies dying from prematurity died on their first day of life at a Level II hospital in greater Minnesota. Their gestational ages ranged from 20 to 22 weeks. Three of the babies weighed less than one pound. One weighed slightly over one pound. The four babies were considered nonviable and died shortly after birth while held by their family members. The fifth baby was born at a Level III hospital at 23 weeks gestation and weighed just over a pound. The baby was treated aggressively and lived for a month but died of complications due to prematurity. (See Appendix E for definitions of hospital levels.)

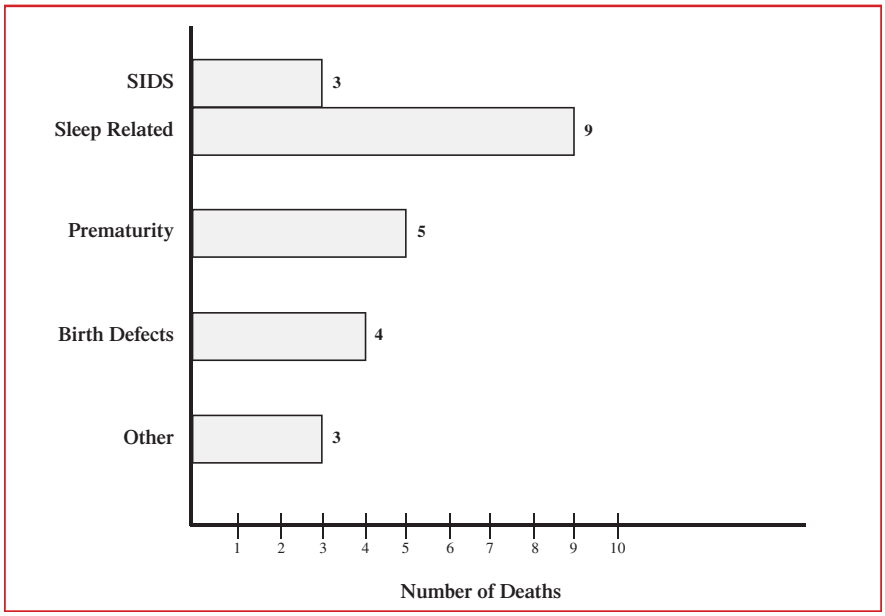
Birth Defects

Four of the 24 babies died of birth defects (17%). Two had heart defects, one had a brain tumor and one had a severe neural tube defect.

Other Causes

The three remaining deaths of the 24 were caused by a motor vehicle crash, homicide and severe sudden illness. (See Figure 3 for causes of American Indian Infant Deaths.)

Figure 3: Causes of American Indian Infant Deaths Reviewed, N=24



Discussion

Data

The high percentage of SIDS and other sleep-related deaths (50%) found in this project is consistent with findings from other studies of American Indian infant deaths. (See Appendix F for causes and timing of deaths of the entire two year cohort.) These findings are consistent with recent data presented by the MDH Center for Health Statistics (Center) on major causes of infant deaths among racial and ethnic populations. Since the risk factors for both SIDS and other sleep-related infant deaths are similar and the parent education messages to reduce the risks are essentially the same, the Center combined the two diagnoses and determined that these deaths were the major cause of death for American Indian infants statewide for the five year period from 2000-2004.

The Center identified prematurity as the second leading cause of infant death and birth defects as the third among American Indians. That determination is consistent with the cases reviewed by this project and provides clear direction for programming and interventions for this population.

Sleep-Related Causes of Death

The finding of SIDS and sleep-related injury as the major cause of infant death provides

the health care system, public health, and community programs with important guidance about where resources and parent education should be directed.

New guidelines for reducing SIDS and preventing sleep-related unintentional injuries were developed and published by the American Academy of Pediatrics (AAP) in November 2005. The AAP also noted that American Indian babies have a SIDS rate that is two to three times higher than the national average.[6]

Minnesota launched the *Safe and Asleep in a Crib of their Own* campaign in July 2007, promoting risk reduction information to families on preventing sleep-related injury deaths that is based on the AAP guidelines. Posters, flyers, and brochures are available for agencies and families provided by the MDH and the Minnesota SID Center.

Culturally Appropriate Strategies

Culturally specific materials on SIDS and infant sleep safety were made available at the Healthy Native Babies training conducted in Minnesota in May 2007. That event was sponsored by the National Institute for Child Health and Human Development and presented by Native American Management Services. The Case Review Team discussed the importance of these materials being widely disseminated to American Indian families, and also suggested that the training should be repeated in Minnesota.

CRT members discussed reasons that parents sleep with their babies. Many families have no crib or have space limitations. Some mothers find that it is easier for breastfeeding and some want to bond with their baby by sleeping with them. Additionally, some mothers do not feel safe either in their communities or in their homes. They want their baby next to them to protect them from dangers they perceive in their environment.
The CRT recommended that resources should be sought to assure safe sleeping arrangements for all American Indian newborns, along with education to the parents and extended family about the importance of a safe sleeping environment for the baby.

Six babies died while sleeping with their father or an adult other than the mother. The CRT felt strongly that fathers and other family members need education about safe infant sleep. “It is not traditional to sleep with your baby”, stated one CRT member. Indian swings were discussed as a culturally appropriate strategy to provide a safe sleep environment while keeping the baby close by.

The maternal interviewers reported that several fathers were present during the interview and asked why more questions were not directed to them. This issue could be addressed with a revision of the interview tool to assure that fathers’ comments are solicited in future projects.

Additional Risk Factors

Avoiding exposure to tobacco smoke during pregnancy (including limiting exposure to secondhand smoke) is an important and well-known way to reduce the risk of SIDS, low birth weight, and prematurity.[7] [8] Culturally specific strategies to reduce smoking and exposure to secondhand smoke are needed and are addressed in the recommendations.

Birth defects were the major cause of infant death for Minnesota's overall population in 2005 and 2006. It is not surprising that there were four deaths related to birth defects in the cases reviewed. Improving preconception health of women of childbearing age, including promoting folic acid use, managing chronic diseases such as diabetes, avoiding toxins, and maintaining a healthy weight should continue to be priorities for women's health and maternal and child health programs.

Quality/Access to Care

Quality and sensitivity of health care provided to mothers is another important area of concern identified by this project. It was of great concern to the CRT that a Level II hospital provided care to mothers of four of the five premature infants reviewed in this project. Three mothers presented at the Level II hospital and one was transferred there by a smaller hospital. Why these four women were not transferred to or sought services of a Level III hospital is unclear.

The CRT identified four cases reviewed where questions arose on the quality of hospital care. Issues discussed included need for hospital protocols to address appropriate care for a woman in premature labor or when an infant dies and the need for community referrals for the family when an infant dies. The CRT discussed the importance of following up on quality of care issues. Recommendations identified for systems change will be disseminated to key staff at birthing hospitals throughout Minnesota.

Level III obstetrical and neonatal intensive care is not available in all areas of the state. One less than ideal approach to address this situation might be to educate women (those at risk for preterm birth) to stay in close contact with a Level III hospital during their pregnancy. Educating women about the importance and value of early and regular prenatal care, as well as early signs and symptoms of preterm labor is another avenue for improving outcomes. Education could be done by prenatal providers, public health nurses on home visits, community health workers, community health representatives and doulas working with the Indian community throughout the state.

Racism

Details of mothers' negative experiences within the health care system were revealed during the review process. The CRT considered and discussed whether these episodes may be evidence of institutional racism. There is research in this area describing the impact of such discrimination on health outcomes. There are valid and reliable questions that can be asked to determine if racial discrimination has occurred.[9] These questions should be included in future infant death reviews to quantify how many mothers perceive they were discriminated against. Discrimination and institutional racism in the health care system is a harmful risk factor that must be identified and remedied if disparities in infant mortality and other health outcomes are to be eliminated.

Hospital Communication

Sensitivity to families in crisis and honest and clear communication about their infant's condition and plan of care from hospital staff were two other key issues identified by the CRT.

Review of Related Literature

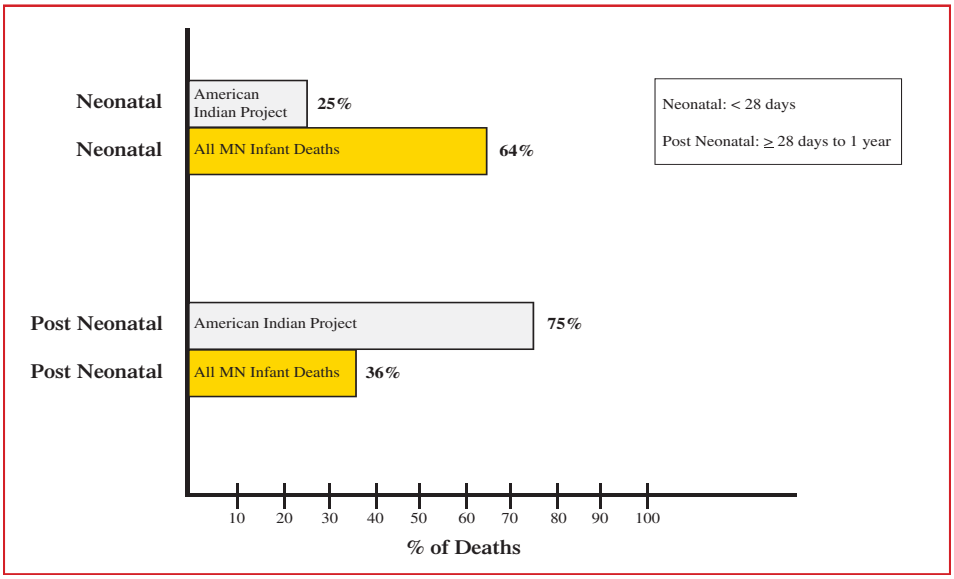
A 2007 national study of American Indian birth outcomes reinforces our project's findings about SIDS and other post neonatal deaths, especially injury deaths. The study found American Indians are not a homogeneous population nationally with south and northeast American Indian women having more preterm and low birth weight babies than the reference group of non-Hispanic whites. In the Midwest, the study's findings were similar to those of this project with post neonatal mortality as the time frame for most deaths and risk factors such as smoking, alcohol use, and delayed prenatal care contributing to the deaths in addition to young maternal age and socioeconomic disparities.[10]

A North Dakota study from 2000 looked at SIDS deaths among American Indian infants before the national Back To Sleep Campaign (1991) and after the campaign was in place for four years (1998). Although American Indian parents adopted the practice of Back To Sleep at a higher rate than White parents (72% vs. 62%), and fewer American Indian parents ever placed their babies to sleep prone even before the campaign, the SIDS rates did not decrease after the campaign was well established. The report indicated that other factors may be more important than sleep position for American Indian babies and suggested that bedding and smoking should be investigated in future research.[11]

Difference in Timing of Deaths

This report highlights an outstanding difference in the American Indian population: the timing of infant deaths from neonatal to post neonatal. To reiterate, 25 percent of American Indian infants died in the neonatal period and 75 percent died in the post neonatal period, whereas Minnesota's overall neonatal and post neonatal death rates are 64 percent and 36 percent, respectively. The recommendations from this report provide guidance for the health care system, city, county and tribal public health and community-based programs to reduce the excess post neonatal deaths of American Indian infants. (See Figure 4, Timing of Infant deaths)

Figure 4: Timing of Infant Deaths 2005-2006, N=24



Limitations

There are inherent limitations in assessing infant mortality in small populations. Each year in Minnesota, there are 1,300 to 1,600 American Indian births. This project covered 2005 and 2006, and during that time, 31 deaths were identified for possible review. The project design required contacting mothers for permission to access their medical records as well as for interviews. By 2007, we were unable to interview several mothers. This was especially true for those whose babies died in 2005 where seven of 11 mothers were non-responsive or not found. Having access to medical records of more mothers and infants would have provided additional information about access and quality of care issues now identified on only 11 of the cases.

Another limitation was the project's inability to ask some mothers for an interview because access was denied at the tribal level. In those cases only vital records and autopsy records were reviewed, and the latter only in the case of a sudden, unexpected death in infancy.

The findings of this project are also limited by having incomplete information on 13 of the 24 deaths that were reviewed and vital records only on an additional seven deaths not reviewed by the CRT because the mothers were not located or declined to participate. The ability to generalize about American Indian infant mortality during the project period is tempered by not being able to interview all 31 mothers for their perspectives.

Recommendations

The following recommendations were developed based on the CRT's reviews of the 24 deaths studied and their knowledge of the population. The recommendations presented in this report include all those generated during the case review brainstorming sessions, discussions, revisions, and editing done by the CRT. They provide the foundation for developing the next phases of the project: prioritizing recommendations, planning action steps, and implementation.

The following overarching recommendations provide insight regarding the CRT's philosophical approach to the issues confronting American Indian childbearing families.

Overarching Recommendations

- Adopt a holistic approach. Mothers and infants exist in families, including extended families and other social networks. Interventions to improve birth outcomes and infant survival must account for the family and community contexts of American Indian mothers and infants.
- Include fathers in all parent education.
- Address men's historic role as protectors of family and community.
- Address the historical trauma of the American Indian experience.
- All education messages should be provided within a cultural context.
- Health and parenting knowledge should be passed on within the community.

The following are specific recommendations from the CRT that are addressed to various systems and key audiences.

Recommendations to Health and Social Service Systems

1. Increase funding directed to prevent teen pregnancy. For example, evidence and outcome-based comprehensive and culturally specific programs for American Indian teens should be available.

2. Increase funding directed to prevent drug and alcohol use/abuse. For example, outreach and awareness activities, afterschool programs that support asset building for youth should be available in the community.

3. Increase collaboration between Child Protection Services and community providers in order to help high-risk teen moms.

4. Reinforce and continue supporting those systems that do work. For example, Minnesota's Level III hospitals generally provide good care for prematurity and birth defects. Refer to Level III hospitals as early as possible.

5. Medical providers' obstetrical protocols and practice should be reviewed regularly.

6. Issues of racism in health care systems need to be addressed.

7. Review all questionable infant deaths in hospitals on an annual basis.

8. Regularly and systematically review American Indian infant deaths in Minnesota.

9. Protocols should be in place in all hospitals related to the time frame in which patients are to be seen by a physician and high risk transfer criteria.

Recommendations to Tribal and Urban Indian Communities

1. Increase public service messages related to prenatal care and infant safety in publications directed at American Indian communities.
2. Increase education to all family and community members about issues related to infant mortality.
3. Increase education (graduation rates) and self-esteem building for American Indian youth.
4. Develop an education campaign targeted to American Indian men about infant mortality and its contributing factors.
5. Provide intensive, holistic, wrap-around services and support for both parents and children dealing with the effects of fetal alcohol exposure.
6. Promote messages that preconceptional care, prenatal care and infant safety are community norms.
7. Offer support and services to families dealing with the death of an infant including support groups.
8. Promote pregnancy and parenting-friendly policies in the workplaces (i.e. private areas for breastfeeding mothers, time off for prenatal appointments, smoke free work environments and time off for bereavement).
9. Take advantage of all venues and methods to repeat consistent health and safety messages.
10. Develop education aimed at the needs and risks of pregnant women who are 35 or older.
11. Promote education on motivational interviewing skills for community educators.
12. Raise awareness in the American Indian community of the need to support their pregnant women.
13. Empower and educate pregnant women and families to stand up for their rights in the medical system.
14. Provide advocates for mothers, particularly teen mothers, to help them navigate social, health and education systems.
15. Develop/improve services to pregnant or parenting adults who are mentally ill, have developmental delays or other conditions that put them at risk for poor parenting.
16. Provide support services, resources and education to grandparents who are raising their grandchildren.
17. Educate and support pregnant and parenting women to stop smoking and to not use alcohol or other drugs.

Recommendations to Medical Providers

1. Assure that the needs of mothers and families are met during pregnancy, labor and delivery, and especially in the event of an infant death.

2. Staff should be trained how to appropriately and sensitively interact and communicate with women and families who have experienced an infant death.

3. Share information about the processes that mothers and families are experiencing in the event of a difficult pregnancy, labor and delivery, and care of a sick infant.

4. Increase availability of medical services (i.e. increase hours/days of service) to meet the diverse needs of those being served.

5. Increase collaboration with community-based organizations to ensure that pregnant women and new mothers and fathers are receiving the services they need.

6. Create specific criteria for care of high risk pregnancies and deliveries, hospital protocols for transfers to Level III hospitals, and response time of a physician when a prenatal patient arrives in an emergency department.

7. Staff should be trained on American Indian cultural issues related to pregnancy, birth and death.

8. Provide comment box for narrative notes in electronic medical records to clarify interventions and patient responses.

9. Offer cytogenic testing and counseling after birth of a baby with a heart defect.

10. Educate families and patients on the importance of vaccinating young girls against human papilloma virus (HPV).

11. Educate families not to give over-the-counter medicine to infants.

12. Provide pregnant women who come to an emergency department with a pregnancy-related complaint with appropriate assessment and treatment.

13. Raise awareness of and address issues of racism and cultural sensitivity in medical systems.

14. Screen pregnant women for alcohol use at every prenatal visit. Provide referrals for services and support as needed.

Recommendations to Systems, Tribal and Urban Indian Communities, & Medical Providers

1. Provide education and services for the whole family related to Sudden Infant Death and infant sleep issues:
    - Help parents understand that co-sleeping and bed sharing is dangerous no matter what the surface.
    - Use traditional infant carrying methods (i.e. slings and cradleboards) to promote safe sleep practices.
    - Infants should sleep on their backs, NOT sides or stomachs.
    - Do not use pillows or soft bedding with infants.
    - Create safe and separate sleep areas for infants, near but not with anyone.
    - Use traditional sleeping methods (i.e. Indian swing safely constructed with baby on his/her back).
    - Sleeping with infants and use of tobacco, alcohol, drugs or medications do not mix.
    - Use safe alternatives if no crib is available (i.e. a laundry basket without fluffy blankets or pillows).
    - Explore why parents sleep with their children in order to help them find safe sleep solutions.

2. Provide education and services related to interconceptional and prenatal care.
    - Women need early and regular prenatal care.
    - Women need preconception care.
    - Educate family and community about family planning and child spacing.
    - Include psychosocial risk assessment in regular prenatal care.
    - Folic acid and prenatal vitamins should be used before and during all pregnancies.
    - Alcohol use screening should be completed at every prenatal visit with support and services for sobriety as well as related issues (i.e. depression, domestic abuse).

3. Provide education and services related to alcohol, tobacco and other drugs during pregnancy and in homes with children.
    - Address use of tobacco during pregnancy.
    - Address exposure to secondhand smoke in homes with children or pregnant women.
    - Address use of alcohol during pregnancy and immediately before pregnancy.
    - Provide supportive, sober housing to pregnant and postpartum women and their children after they leave treatment so they can maintain their sobriety and stay drug free.

Continued...

Recommendations to Systems, Tribal and Urban Communities, & Medical Providers (continued)

4. Provide education and assistance to families related to car seats.
    - Provide car seat safety education to pregnant and parenting families.
    - Provide education about projectiles in vehicles.

5. Promote the health of both mothers and infants by educating and supporting mothers to breastfeed their infants for at least 12 months.

6. Increase education and services related to grieving issues.
    - Provide culturally specific grief support.
    - Recognize that different people handle grief differently.
    - Increase awareness among behavioral health and spiritual advisors about how to deal with an infant death.
    - Do not talk to parents as though the baby never existed.
    - Remember other children in a family when an infant dies.
    - Remember the father when an infant dies.
    - Educate schools to work with kids who have had a sibling pass away.
    - Do not tell grieving parents it is time to "move on."
    - Assist parents in providing for culturally appropriate or generally appropriate funeral and burial arrangements.
    - Provide easier access to funeral and burial services.

During the interviews, mothers (and the grandmother) were asked for their advice. Their comments are summarized below.

Mothers' Advice to Programs

1. Community programs should get involved when an American Indian woman is pregnant to reduce the higher infant death rate.

2. School counselors should be supportive of siblings when a baby dies.

3. Tribes should be supportive of grieving enrolled members and remove barriers to financial services.

4. There should be more grief support programs. Most are in the urban area and not easy to get to.

5. It is appreciated when investigators ask questions in a sensitive manner at the time of death.

6. Reach out to grieving parents (i.e. Send information or an invitation to a support group).

Mothers' Advice to Health Care Providers

1. Don't assume. Be kind and considerate, not judgmental.

2. When pregnant women come to the ER, ask if they need more help. Don't let them leave until you are sure they are okay.

3. Providers should explain things in terms that families understand.

4. Tell parents the truth about what is happening and that the baby might die.

5. Make time to get to know patients.

6. Be sensitive to the needs and emotions of the parents at the time of the death.

7. For clinics: Be more attentive to patients' needs; schedule fewer patients; communicate better among staff.

8. For nurses: remember you are there for the patient; if a nurse is not clicking with a patient, please get a different nurse.

Mothers' Advice to Families

1. Friends and family should stay close. Comfort and just be there.
2. Be willing to help the grieving parents whenever you can.
3. Do not generalize about why babies die.
4. Families should talk about the baby and his or her death even when the baby's life was short.
5. Turn to someone who can help you get in touch with the Creator and your spiritual side. It helps you see ahead to a better day.
6. Recognize that people handle grieving differently.
7. Face reality and move on.
8. Just don't blame yourself and always remember the baby.
9. Pregnant women should try not to use drugs and alcohol.
10. Parents who lose a baby should think about the needs of their other children.
11. Time really does heal.
12. For relatives and friends: Say something, even just "I'm sorry."
13. Never tell parents it is time to move on or that you can have another baby.
14. Take time to think about where you want your baby to rest.
15. Join a support group right away. It helps to meet others with similar situations.
16. For grieving families: Focus on the people still alive. They have to find a comfort level in talking about the death.
17. For relatives and friends: Be sensitive. Listen. "I know how you feel" is not a good thing to say.

Next Steps

This report documents the process and findings of the American Indian Infant Mortality Review and includes the complete list of recommendations generated by the Case Review Team. This report will be disseminated to all appropriate audiences who work with or provide health care services to American Indian women. This report will initially be sent to the eleven sovereign tribal nations of Minnesota, the urban Indian organizations, the Bemidji Area Indian Health Service, local public health agencies, and the hospitals and health care systems serving American Indians living in Minnesota.

The next steps in this process will be to review and refine the recommendations generated by the Case Review Team, then develop and implement actionable strategies that will reduce the number of infant deaths within Minnesota's American Indian community.

Endnotes

[1] Koontz A, Buckley K, Ruderman M. The evolution of fetal and infant mortality review as a public health strategy. *Matern Child Health J*. 2004; 8: 195-203.

[2] Communication with the Center for Health Statistics, MDH. 2008

[3] Center for Health Statistics, MDH. *Populations of Color in MN: Health Status Report*. 2007.

[4] Center for Health Statistics, MDH. *Minnesota Health Statistics, Annual Summary*. 2005 & 2006.

[5] American Academy of Pediatrics Task Force on SIDS. The changing concept of Sudden Infant Death Syndrome: Diagnostic shifts, controversies regarding the sleep environment, and new variables to consider in reducing risk. *Pediatrics*. 2005; 116:1245-1255.

[6] Ibid.

[7] Shah T, Sullivan K, Carter J. Sudden Infant Death Syndrome and reported maternal smoking during pregnancy. *AJPH*. 2006; 96:1757-1759.

[8] Wisborg K, Kesmodel U, Henriksen T, Olsen S, Secher N. A prospective study of smoking during pregnancy and SIDS. *Archdischild*. 2000; 83: 203-206.

[9] Krieger N, Smith K, Naishadham D, Hartman C, Barbeau EM. Experiences of discrimination: Validity and reliability of a self-report measure for population health research on racism and health. *Soc Sci Med*. 2005; 61: 1576-1596.

[10] Alexander G, Wingate M, Boulet S. Pregnancy outcomes of American Indians: Contrasts among regions and with other ethnic groups. *Matern Child Health J*. 2007; Springer.

[11] McCulloch K, Dahl S, Johnson S, Burd L, Klug M, Beal J. Prevalence of SIDS risk factors: Before and after the “Back to Sleep” campaign in North Dakota Caucasian and American Indian infants. *Clinical Pediatrics*. 2000; 403-410.

Appendix A:
Project Letters

January, 2007

Tribal Chairs and Tribal Health Directors:

Recently, statistics were presented about the high rates of American Indian infant deaths in Minnesota, particularly on the northwestern reservations in the state. According to death certificate data gathered by the Minnesota Center for Health Statistics, Minnesota's American Indian infant mortality rate for the years 1999-2003 was 9.9 deaths per 1,000 births, while the rate for the White population during that period was 4.8 deaths per 1,000 births, less than half the American Indian rate. In order to try to understand and address some the factors that lead to this disparity, the Maternal and Child Health Section of the Minnesota Department of Health (MDH) requested and was awarded funds to conduct an American Indian Infant Mortality Review. This project is in line with discussions held with representatives from Red Lake, White Earth, Leech Lake and tribal nursing directors.

The goal of the American Indian Infant Mortality Review is to work with a team of health and social service workers and community members from the Indian communities to determine medical, social, and environmental factors that contribute to these deaths, such as barriers to care, gaps in services and community trends. The team will then make recommendations for improving systems of care and services provided during pregnancy and infancy with the aim of improving American Indian birth outcomes.

The individuals involved in the project will be American Indians and other health professionals. Specific attention will be given to assure that the process used to conduct the interviews with the mothers and to review the information on each death will be done respectfully. Each case reviewer will sign a confidentiality agreement. Also, all identifying information will be blacked out, and reporting of the results of the review and the recommendations will be reported in the aggregate.

We look forward to working together with you and other tribal members in conducting the American Indian Infant Mortality Review. Please feel free to contact Cheryl Fogarty at 651-201-3740 or cheryl.fogarty@state.mn.us if you have any questions, comments or concerns about this review. We anticipate that results and recommendations will be available for you in the fall of 2007.

Respectfully,

Sharon Smith
Tribal Health Liaison
Office of Minority and Multicultural Health
Minnesota Department of Health

January, 2007

Kathy Annette, MD
Director of Bemidji Area Indian Health Service

We are in the process of working on a statewide American Indian infant mortality project and want to keep you informed as we proceed. Recent statistics were presented about the high rates of American Indian infant deaths in Minnesota, particularly on the northwestern reservations in the state. According to death certificate data gathered by the Minnesota Center for Health Statistics, Minnesota's American Indian infant mortality rate for the years 1999-2003 was 9.9 deaths per 1,000 births, while the rate for the White population during that period was 4.8 deaths per 1,000 births, less than half the American Indian rate. In order to try to understand and address some the factors that lead to this disparity, the Maternal and Child Health Section of the Minnesota Department of Health (MDH) requested and was awarded funds to conduct an American Indian Infant Mortality Review. This project is in line with discussions held with representatives from Red Lake, White Earth, Leech Lake and tribal nursing directors.

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We will keep you informed about the progress and final results of the American Indian Infant Mortality Review. Please feel free to contact Cheryl Fogarty at 651-201-3740 or cheryl.fogarty@state.mn.us if you have any questions, comments or concerns about this review. We anticipate that we will share results and recommendations with you the fall of 2007.

Respectfully,

Sharon Smith
Tribal Health Liaison
Office of Minority and Multicultural Health
Minnesota Department of Health

MINNESOTA MDH DEPARTMENT OF HEALTH

Protecting, maintaining and improving the health of all Minnesotans

February 2, 2007

Cheryl Fogarty
Infant Mortality Consultant
Minnesota Department of Health
85 East Seventh Place, Suite 500
St. Paul, MN 55101

Re: IRB #06-151
IRB Original Review Date: December 21, 2006
Re-Review due in IRB Administrative.Office: October 5, 2007
Approval Expires: December 21, 2007

Dear Cheryl:

Thank you for submitting your responses to the stipulations for your proposal IRB #06-151, entitled "American Indian Infant Mortality Review" to the Minnesota Department of Health's (MDH) Institutional Review Board (IRB) for review.

Your responses were reviewed and have been approved by the Board.

Please send a final copy of the interview form for our records.

As Principal Investigator of this project, you are required by federal regulations to inform the IRB of any proposed changes in your research that will affect human subjects. Changes should not be initiated until written IRB approval is received. Adverse events must be reported to the Board as they occur. Research projects are subject to continuing review and renewal. You will receive a Re-Review Form approximately one month prior to the approval expiration date noted above.

Please note that your project has been assigned a five-digit code number (above). Please use this five-digit number and the title of your study in all future communications with the IRB office

Cordially,

Peter Rode
IRB Administrator
651-201-5942

cc: Ann Kowski

MINNESOTA DEPARTMENT OF HEALTH
MDH

Protecting, maintaining and improving the health of all Minnesotans

November 7, 2007

Cheryl Fogarty
Minnesota Department of Health
85 East Seventh Place, Suite 500
St. Paul, MN 55164

RE: IRB #06-151
IRB Original Review Date: December 21, 2006
Re-review due in IRB Administrative Office: October 3, 2008
IRB Approval Expires: December 21, 2008

Dear Cheryl:

Thank you for submitting your Re-review of Previously Approved Research form for your project IRB #06-151 entitled "American Indian Infant Mortality Review" to the Minnesota Department of Health's (MDH) Institutional Review Board (IRB) for review.

The Board has reviewed the information submitted using an expedited review process and approved the proposal for an additional year. Your approval for this project will expire on **December 21, 2008**. A Re-review form will be sent to you two months before the expiration date.

As Principal Investigator of this project, you are required by federal regulations to inform the IRB of any proposed changes in your research that will affect human subjects. Changes should not be initiated until written IRB approval is received. Adverse events must be reported to the Board as they occur. Research projects are subject to continuing review and renewal.

Please note that your project has been assigned a five-digit code number (above). Please use this five-digit code number **and** the title of your study in all future communications with the IRB office.

Good luck with your research.

Sincerely,

Peter Rode

Peter Rode
IRB Administrator
PO Box 64882
St. Paul, MN 55164-0882
651-201-5942

cc:
Ann Kowski

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Indian Health Service
Research Program
801 Thompson Avenue
Rockville, MD 20852

May 9, 2007

Cheryl Fogarty,
Infant Mortality Consultant
Minnesota Department of Health
85 East Seventh Place, Suite 500
St. Paul, MN 55101

RE: **Protocol # N07-BE-05: "American Indian Infant Mortality Review" – APPROVED**

Dear Ms Fogarty:
The Indian Health Service (IHS) National Institutional Review Board (IRB) has expedited the review of your protocol entitled, "American Indian Infant Mortality Review," as allowed under 45 CFR 46.110(b)(1). The IRB **approves** your protocol. Your study is judged to be of **minimal risk** to human subjects. This decision is based on the information you provided which shows:

- Study "interventions" of maternal interviews, to be conducted by specially selected and trained individuals, represent a minimal risk to subjects;
- There are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data; and
- The study has the support of the community.

This approval is contingent on use of the revised consent form submitted to us on April 24th, 2007. Please contact your other IRB(s) to determine what review may be required on their part, for these changes. If you encounter problems in this area, please contact the IHS Human Research Protection Administrator, Dr. Alan Trachtenberg, who will assist you in the coordination of approvals with the other IRB(s).

This approval is valid through May 8, 2008. Any further anticipated changes in the protocol must be reviewed with this office prior to implementation. Publications resulting from this research must be cleared with the NIRB. If you have any questions about the IHS NIRB review or decision, please contact me at (301)443-1549, or Dr. Alan Trachtenberg at (301)443-0578. You may also email the IRB at IRB@IHS.gov. Correspondence should be sent directly to the IHS-NIRB, Office of Public Health Support, 801 Thompson Ave., TMP 450, Rockville, MD 20852. We appreciate your interest in providing the benefits of health research to American Indian and Alaskan Native children and families.

Sincerely,

Phillip L. Smith, MD, MPH
Chair, IHS National IRB (NIRB)
IRB00000646
FWA00008894

Date

Dear

We were very sorry to learn of the death of your baby, _____. This is a tragedy for you and your family and is also a loss to our entire community. While we know there is nothing we can do to ease your loss, we are trying to prevent another family from having this experience. As we ask for your help, please remember that you have our deepest sympathy and we do not intend to add to your pain.

We believe there are too many infant deaths among American Indian families in Minnesota. We are asking you to help us learn more about the death of _____so we can try to prevent future American Indian infant deaths. We are inviting you to participate in Minnesota's American Indian Infant Mortality Review Project that will study a number of deaths to see how the system of care for pregnant women and their babies can be improved.

You will be contacted by our interviewer, _____, who will ask you to meet and talk with her about what happened during pregnancy and about your baby's life and death. We realize this may be a painful discussion for you. However, it is very important to hear from mothers themselves about what they actually experienced. All information you provide will be kept confidential and not shared with anyone except project staff. Most of the people working on this project are American Indians and are very dedicated to this project. We have spent a lot of time making sure this process will be as painless as possible.

You have the right to decline to participate and you can let _____know that when she contacts you. To thank you if you do decide to participate, you will receive two gift cards from Walmart each worth $50.00. _____will provide one card and you will receive the second one in the mail shortly after the interview is completed.

If you have any questions about this project, please feel free to contact Cheryl Fogarty, Project Coordinator, at 651-201-3740 or email: cheryl.fogarty@state.mn.us. Also, feel free to contact either one of us if you need additional information about how this project was planned.

Thank you in advance if you decide to participate in this important project.

Sincerely,

Sharon Smith, Tribal Health Liaison
Office of Minority and Multicultural Health
651-201-5820

Valerie Larsen, Urban Indian Health Consultant
Office of Minority and Multicultural Health
651-201-5817

Appendix B: Maternal Interview Training Agenda & Interview Tool

American Indian Infant Mortality Review Project

Minnesota Department of Health

Training for Maternal Interviewers

Thursday, February 22, 2007
9:30 am-1:30 pm
St. Paul, Minnesota

Friday, February 23, 2007
11:00 am-3:00 pm
Bemidji, Minnesota

Overview of the project: need, purpose, history of the methods

Begin review of the interview instrument: quantitative questions & taping of open ended questions

Overview of confidentiality; consent forms: HIPPA & consent to participate

Mandated reporting

Lunch

Continue review of the interview instrument

Bereavement: normal vs. complicated grief; resources for referral

Incentive: Walmart gift card

Data practices agreement; other contract issues

Ask if mother wants to receive project report

Final questions, discussion

Case assignments

CONFIDENTIAL

Maternal Interview Questionnaire

American Indian Infant Mortality Review

2007

Minnesota Department of Health
Division of Community and Family Health
Maternal and Child Health Section
PO Box 64882
St. Paul, MN 55164-0882

Getting Ready And Beginning The Interview

General Instructions

Be familiar with the questions and instructions for the questionnaire before beginning the interview.

Ask the mother how she would like for you to refer to the baby (i.e. by his or her name on the birth certificate or his/her spirit name).

Caution the mother, that it sometimes may be hard to discuss her baby's death and that she can ask at any time for the interviewed to be stopped.

Explain to the mother that you would like to tape record the interview, if she agrees. (E.g. "I could listen more closely" or "staff will learn your story in your own words.") You may have other good ideas to introduce the tape recording of the interview.

Remain sensitive to the mother's need to expound on or digress from any particular event(s) that generate(s) strong feelings and to give her time to recall details and relate experiences in her own words.

Remind the mother that if at any time during the interview if she does not want to answer any question, to let you know and the question will be skipped.

Begin the Interview

(TURN ON THE TAPE RECORDER)

Once a comfortable atmosphere has been achieved, the best way to begin the interview is to ask the mother to describe, in her own words, the events leading up to the death of her infant. The mother may have already started telling you about the death before you had to ask.

1. Tell me about what happened when _____ died.
   PROBES

   Was it a sudden or unexpected death or had _____ been ill?
   Was there anything different about that day?

   If sudden and unexpected and the baby died at home or daycare:
   Did anyone call for help? If so, who did they call?
   What kind of transportation was used?

2. What is your understanding of what caused _____'s death?

3. How was _____'s death explained to you?

   PROBES

   Who talked with you? (E.G. family MD, pediatrician, obstetrician, specialist MD, coroner/medical examiner, ER doctor, EMS personnel, others)

   What did he/she tell you?

   What have others told you? (E.g. baby's father, relatives, friends, neighbors, people at work, funeral home directors, law enforcement, social workers, clergy, counselors, health plans, insurance, others).

(TURN OFF THE TAPE RECORDER)

Part A – Prenatal Care

1. How many weeks or months pregnant were you when you were *sure* you were pregnant? (e.g., a doctor or nurse said you were pregnant or you had a pregnancy test at home or at a clinic)

_____ Weeks
_____ Months
_____ Don't know/Refused (circle one)

2. How many weeks or months pregnant were you when you had your first visit for prenatal care? Do not count a visit that was only for a pregnancy test or only for WIC (the Special Supplemental Nutrition Program for Women, Infants, and Children).

_____ Weeks
_____ Months
_____ I did not have prenatal care (skip to question 4)
_____ Don't know/Refused (circle one)

3. Did you get prenatal care as early in your pregnancy as you wanted?

☐ No
☐ Yes
☐ Don't know/refused (circle one)

4. Here is a list of problems some women encounter when trying to get prenatal care. For each item, indicate "Yes" if it was a problem for you during your most recent pregnancy or "No" if it was not a problem. If mother refused to answer, ask to skip the question, or "Ref" (Refused)

☐ Yes ☐ No ☐ Ref a. Couldn't get an appointment when I wanted one
☐ Yes ☐ No ☐ Ref b. Didn't have enough money or insurance to pay for my visits
☐ Yes ☐ No ☐ Ref c. Had no way to get to the clinic or doctor's office
☐ Yes ☐ No ☐ Ref d. Couldn't take time off from work
☐ Yes ☐ No ☐ Ref e. The doctor or my health plan would not start care as early as I wanted
☐ Yes ☐ No ☐ Ref f. Didn't have my Medical card
☐ Yes ☐ No ☐ Ref g. Had no one to take care of my children
☐ Yes ☐ No ☐ Ref h. Didn't want anyone to know I was pregnant
☐ Yes ☐ No ☐ Ref i. Had too many other things going on
j. Other (specify)

5. Please tell us:
How was your prenatal care paid for? Check all that apply. (If no prenatal care, skip to question 8)

☐ Refused/don't know (circle one)
☐ Health insurance or HMO (including insurance from your work or your husband's work)
☐ Indian Health Service
☐ Medicaid, Medical Assistance, or MinnesotaCare

☐ Personal income (cash, check, or credit card)
☐ Tribal health service
☐ Other (specify):

6. How long did it usually take you to travel one way to the place you received most of your prenatal care?

_____ Hours
_____ Minutes
_____ Don't Know/NA/Refused (circle one)

7. We would like to know how you felt about the prenatal care you got during your pregnancy with ____. If you went to more than one place for prenatal care; answer for the place where you got most of your care. For each item, indicate "Yes" if you were satisfied or "No" if you were not satisfied. If no prenatal care, skip to question 9. Were you satisfied with:

☐ Yes ☐ No ☐ Ref The amount of time the doctor or nurse spent with you during your visits?
☐ Yes ☐ No ☐ Ref The advice you got on how to take care of yourself?
☐ Yes ☐ No ☐ Ref The understanding and respect that the staff showed toward you as a person?

8. The following are problems that can occur during or before pregnancy? For each item, indicate "Yes" if your had any of these problems when you were pregnant with ___ or "No" if you did not have any of these problems when you were pregnant with ___. You can also say that you do not wish to respond.

☐ Yes ☐ No ☐ Ref a. High blood sugar (diabetes) that started before this pregnancy
☐ Yes ☐ No ☐ Ref b. High blood sugar (diabetes) that started during this pregnancy
☐ Yes ☐ No ☐ Ref c. Vaginal bleeding
☐ Yes ☐ No ☐ Ref d. Kidney or bladder (urinary tract) infection
☐ Yes ☐ No ☐ Ref e. Severe nausea, vomiting, or dehydration
☐ Yes ☐ No ☐ Ref f. Cervix had to be sewn shut (incompetent cervix)
☐ Yes ☐ No ☐ Ref g. High blood pressure, hypertension (including pregnancy-induced hypertension [PIH], preeclampsia, or toxemia)
☐ Yes ☐ No ☐ Ref h. Problems with the placenta (such as placental abruption or placenta previa)
☐ Yes ☐ No ☐ Ref i. Labor pains more than 3 weeks before my baby was due (preterm or early labor)
☐ Yes ☐ No ☐ Ref j. Water broke more than 3 weeks before my baby was due (premature rupture of membranes [PROM])
☐ Yes ☐ No ☐ Ref k. I had to have a blood transfusion
☐ Yes ☐ No ☐ Ref l. I was hurt in a car accident
☐ Yes ☐ No ☐ Ref m. I was physically abused during my pregnancy

If any responses are yes, continue to question 9. If all "no" responses go to question 10.

9. Did you do any of the following things because of problems you identified in the previous question? Indicate "Yes" if you did that thing or "No" if you did not. You can also refuse the question.

☐ Yes ☐ No ☐ Ref a. I went to the hospital or emergency room and stayed less than 1 day
☐ Yes ☐ No ☐ Ref b. I went to the hospital and stayed 1 to 7 days
☐ Yes ☐ No ☐ Ref c. I went to the hospital and stayed more than 7 days
☐ Yes ☐ No ☐ Ref d. I stayed in bed at home more than 2 days because of my doctor's or nurse's advice

10. During your pregnancy, did you attend or receive any of the following? (Indicate "yes" for all that apply or "no" if you did not attend or receive the following. You can also refuse the question.

☐ Yes ☐ No ☐ Ref Childbirth education classes
☐ Yes ☐ No ☐ Ref Child safety instruction (including using infant car seats or infant sleep position)
☐ Yes ☐ No ☐ Ref Parenting classes
☐ Yes ☐ No ☐ Ref Counseling about stress, family problems, or mental problems
☐ Yes ☐ No ☐ Ref Visits from a PHN
☐ Yes ☐ No ☐ Ref Visits from a doula
☐ Yes ☐ No ☐ Ref Visits from a home care nurse
☐ Yes ☐ No ☐ Ref None/Don't Know

11. When you got pregnant with ___, were you trying to get pregnant?

☐ No
☐ Yes
☐ Don't know/Refused (circle one)

12. When you got pregnant with ___, were you or your husband or partner doing anything to keep from getting pregnant?

☐ No
☐ Yes
☐ Refused
If yes, specify method:

13. If your doctor or nurse-midwife advised you to rest in bed, were you able to stay in bed as long as recommended?

☐ Yes
☐ No (if no, indicate "yes" or "no" for the reasons below)

☐ Yes ☐ No No Help at home
☐ Yes ☐ No Had to go to appointments
☐ Yes ☐ No Had to go to work
☐ Yes ☐ No Other (specify)
☐ NA/refused (circle one)

14. Would you say that, in general, your health during your pregnancy with ___ was?

☐ Good
☐ Fair
☐ Poor
☐ Don't know/refused

15. Is there anything else you would like to tell me about your pregnancy?

Part B – Nutrition, Weight Gain, And Health Habits

16. How much did you weigh during the three months before you became pregnant with _____?

_____ Pounds
_____ Don't know/refused (circle one)

17. How tall are you without shoes?

_____ Feet / Inches
_____ Don't know/refused (circle one)

18. How much weight did you gain during your pregnancy with _____?

_____ Pounds
_____ Don't know/refused (circle one)

19. Did a health care worker tell you how much weight you should gain during your pregnancy with ___?

☐ Yes
☐ No
☐ Don't know/refused (circle one)

If yes, what did they tell you?
_____ Pounds

20. Did you eat a special diet during your pregnancy with _____?

☐ No
☐ Yes

If yes, specify (special organic, vegetarian, native foods):
If yes, specify who recommended:

21. During your pregnancy with _____, did you see a special diet counselor? (i.e. registered dietitian, WIC nutrition counselor)

☐ Yes
☐ No

☐ Don't know/ Refused (circle one)

If yes, why? (e.g. gestational diabetes, poor nutrition, anemia, weight control, weight loss etc.)

22. Some families hunt or fish for food. Did you eat any food gathered this way during your pregnancy with _____?

☐ Yes
☐ No
☐ Don't know/refused (circle one)

If yes, specify (e.g. venison, fish)

Where was it gathered? (e.g. lake, woods)

How often did you eat these foods? (e.g. weekly, daily)

23. During your pregnancy with ___, were you on WIC (the Special Supplemental Nutrition Program for Women, Infants, and Children)?

☐ Yes
☐ No
☐ Don't know/refused (circle one)

24. During your pregnancy was there a time when you and your family needed food but couldn't afford to buy it?

☐ Yes (if yes go to 24A
☐ No
☐ Don't know/refused (circle one)

24a. If yes, when that happened, did some person or organization help you get food?

☐ Yes
☐ No
☐ Don't know/refused (circle one)

If yes, who helped you?

The next questions are about smoking cigarettes, drinking alcohol, & taking medications

25. In the 3 months before you got pregnant with ___, how many cigarettes did you smoke on an average day? (A pack has 20 cigarettes.)

☐ 41 cigarettes or more
☐ 21 to 40 cigarettes
☐ 11 to 20 cigarettes

- ☐ 6 to 10 cigarettes
- ☐ 1 to 5 cigarettes
- ☐ Less than 1 cigarette
- ☐ None (0 cigarettes)
- ☐ Refused

26. In the last 3 months of your pregnancy with ___, how many cigarettes did you smoke on an average day? (A pack has 20 cigarettes.)

- ☐ 41 cigarettes or more
- ☐ 21 to 40 cigarettes
- ☐ 11 to 20 cigarettes
- ☐ 6 to 10 cigarettes
- ☐ 1 to 5 cigarettes
- ☐ Less than 1 cigarette
- ☐ None (0 cigarettes) Skip to question 28
- ☐ Refused

27. How many cigarettes do you smoke on an average day now? (A pack has 20 cigarettes.)

- ☐ 41 cigarettes or more
- ☐ 21 to 40 cigarettes
- ☐ 11 to 20 cigarettes
- ☐ 6 to 10 cigarettes
- ☐ 1 to 5 cigarettes
- ☐ Less than 1 cigarette
- ☐ None (0 cigarettes)
- ☐ Refused

28. During the 3 months before you got pregnant with ___, how many alcoholic drinks did you have in an average week?

- ☐ 14 drinks or more a week
- ☐ 7 to 13 drinks a week
- ☐ 4 to 6 drinks a week
- ☐ 1 to 3 drinks a week
- ☐ Less than 1 drink a week
- ☐ I didn't drink then (skip to question 31)
- ☐ Refused

29. During the 3 months before you got pregnant with ___, how many times did you drink 5 alcoholic drinks or more in one sitting?

- ☐ 6 or more times
- ☐ 4 to 5 times
- ☐ 2 to 3 times
- ☐ 1 time
- ☐ I didn't have 5 drinks or more in 1 sitting
- ☐ I didn't drink then
- ☐ Refused

30. During the last 3 months of your pregnancy with ___, how many alcoholic drinks did you have in an average week?

- ☐ 14 drinks or more a week
- ☐ 7 to 13 drinks a week
- ☐ 4 to 6 drinks a week
- ☐ 1 to 3 drinks a week
- ☐ Less than 1 drink a week
- ☐ I didn't drink then
- ☐ Refused

31. How many drinks do you have in an average week now?

- ☐ 14 drinks or more a week
- ☐ 7 to 13 drinks a week
- ☐ 4 to 6 drinks a week
- ☐ 1 to 3 drinks a week
- ☐ Less than 1 drink a week
- ☐ I don't drink now
- ☐ Refused

32. Because of your pregnancy with ___ did you stop taking any medications prescribed to treat a health condition?

- ☐ Yes
- ☐ No (skip to question 33)
- ☐ Don't know/refused (circle one)

32a If yes, name of medication(s)

32b If yes, was a health worker monitoring your condition during your pregnancy?

- ☐ Yes
- ☐ No
- ☐ Don't know/refused (circle one)

33. Were you taking any prescription medication(s) during your pregnancy?

- ☐ Yes (if Yes – respond to 33a)
- ☐ No (if No – go to question 34)
- ☐ Don't know/refused (circle one)

33a. If yes, name of medication(s)

33b If yes, was a health worker monitoring your condition during your pregnancy?

- ☐ Yes
- ☐ No
- ☐ Don't know/refused (circle one)

34. Were you taking any over the counter, nonprescription, or other medicines during your pregnancy?

- ☐ Yes
- ☐ No (if No skip to question 35)
- ☐ Don't know/refused (circle one)

34a. If yes, name of medication(s)

34b. How often? (e.g. daily, weekly, as needed)

34c. If yes, was a health work monitoring your condition during your pregnancy?

- ☐ Yes
- ☐ No
- ☐ Don't know/refused (circle one)

35. Were you taking any street drugs or other drugs during your pregnancy?

- ☐ Yes
- ☐ No (if no, skip to question 36)
- ☐ Don't know/refused (circle one)

35a. How often? (e.g. daily, weekly, as needed)

36. Is there anything else you would like to tell me about your nutrition or health habits? (diet habits, eating habits, Was your nutrition – good, fair, poor?)

Part C — Delivery Of Baby

37. Please tell me about your labor and delivery, how did it go? (indicate if question refused)

38. How was your delivery paid for? Check all that apply

- ☐ Health insurance or HMO (including insurance from your work or your husband's work)
- ☐ Indian Health Service
- ☐ Medicaid, Medical Assistance, or MinnesotaCare
- ☐ Personal income (cash, check, or credit card)
- ☐ Tribal health service
- ☐ Other (specify)

39. Were you satisfied with the care you and your baby received during your delivery and hospitalization?

- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Dissatisfied
- ☐ Don't know/refused (circle one)

Please explain

40. Did your baby go home with you?

☐ No
☐ Yes
☐ Don't know/refused (circle one)
☐ Baby came home later
☐ Baby never came home (see NOTE below).

NOTE: If the baby did not come home, SKIP the Supplement "Baby's Health at Home" and go to page 23.

Supplement – Baby's Health at Home

These questions are about the care of your baby at home. We know that some questions may be difficult to answer and some may be a painful reminder. Please give us whatever information you can. We are asking these questions so that we can try to help other women with their pregnancies.

41. How old was ___ when he/she *first* came home from the hospital?

_____ Days
_____ Months
_____ Don't know/refused (circle one)

42. Did a health care worker talk with you about any of these topics before you left the hospital with ___ ? Indicate yes, no, refused. (Y, N, R)

☐ Soothing your baby
☐ Feeding your baby
☐ Clothing and bathing your baby
☐ How to tell if your baby is getting enough to eat
☐ Preventative health care for your baby
☐ How to tell if your baby is sick
☐ Who to call when your baby is sick
☐ Infant sleep environment
☐ Safety issues (including car seat safety)
☐ Violence issues
☐ Post partum blues/depression

43. Did you feel ready to begin taking care of a new baby when ___ came home?

☐ No
☐ Yes
☐ Don't know/refused (circle one)

If no, please explain:

44. Did you have everything you needed to care for ___ at home?

☐ No
☐ Yes
☐ Don't know/refused (circle one)

If no, please explain:

45. Did you have a follow-up medical appointment scheduled for ___?

☐ No
☐ Yes
☐ Don't know/refused (circle one)

46. Did the staff arrange for a PHN or home health nurse to visit you at home after discharge?

☐ No (If no, skip to 47)
☐ Yes (if yes, indicate if PHN or home health nurse)
☐ Don't know/refused (circle one)

46a If yes, how did this visit go?

47. Did you ever breastfeed or pump breast milk to feed ___ after he/she was born?

☐ No → skip to Question 49
☐ Yes
☐ Refused

48. How many weeks or months did you breastfeed or pump milk to feed to _____?
_____ Weeks
_____ Months
_____ Less than 1 week

49. What were your reasons for not breastfeeding your new baby? Indicate "Yes" if you agree with the statement or "No" if you do not agree. You can also refuse/skip the question (NA).

☐ Yes ☐ No ☐ Ref My baby was sick and could not breastfeed
☐ Yes ☐ No ☐ Ref I was sick or on medicine
☐ Yes ☐ No ☐ Ref I had other children to take care of
☐ Yes ☐ No ☐ Ref I had too many household duties
☐ Yes ☐ No ☐ Ref I didn't like breastfeeding.
☐ Yes ☐ No ☐ Ref I didn't want to be tied down
☐ Yes ☐ No ☐ Ref I was embarrassed to breastfeed
☐ Yes ☐ No ☐ Ref I went back to work or school
☐ Yes ☐ No ☐ Ref I wanted my body back to myself
☐ Yes ☐ No ☐ Ref Other: specify_____

50. What were your reasons for stopping breastfeeding? Indicate "Yes" if you agree with the statement or "No" if you do not agree. You can also refuse/skip the question.

☐ Yes ☐ No ☐ Ref My baby had difficulty nursing
☐ Yes ☐ No ☐ Ref Breast milk alone did not satisfy my baby
☐ Yes ☐ No ☐ Ref I thought my baby was not gaining enough weight
☐ Yes ☐ No ☐ Ref My baby got sick and could not breastfeed
☐ Yes ☐ No ☐ Ref My nipples were sore, cracked, or bleeding
☐ Yes ☐ No ☐ Ref I thought I was not producing enough milk
☐ Yes ☐ No ☐ Ref I had too many other household duties
☐ Yes ☐ No ☐ Ref I felt it was the right time to stop breastfeeding
☐ Yes ☐ No ☐ Ref I got sick and could not breastfeed
☐ Yes ☐ No ☐ Ref I went back to work or school
☐ Yes ☐ No ☐ Ref I wanted or needed someone else to feed the baby
☐ Yes ☐ No ☐ Ref My baby was jaundiced (yellowing of the skin or whites of the eyes)
☐ Yes ☐ No ☐ Ref Other: specify _____

51. Was ___ ever in the same room with someone who was smoking?

☐ No (if no, skip to question 52)
☐ Yes
☐ Refused

51a. If yes, indicate the approximate length of time __ was in the same room with someone who was smoking
_____ daily
_____ number of hours
_____ Less than 1 hour a day
_____ Occasionally/rarely

52. How did you most often lay ___ down to sleep? Indicate how you most often laid them down to sleep

☐ On his or her side
☐ On his or her back
☐ On his or her stomach

53. Describe the sleep environment (e.g. shared bed, crib)

54. Did you go to work or school after ___ was born?

☐ No (skip to question 55)
☐ Yes
☐ Refused

If yes, how old was ___
_____ in weeks or _____ months

54a. If yes, who provided the most baby care?

- ☐ A relative or friend
- ☐ Father of baby
- ☐ Partner, not FOB
- ☐ Tribal child care center
- ☐ Licensed home-based provider
- ☐ Private day-care facility
- ☐ Self, kept baby with me
- ☐ Other (specify)_____
- ☐ Refused

55. Was ___ seen by a doctor, nurse, or other health care worker during the first week or two after he or she left the hospital?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused (circle one)

56. Did ___ have a well-baby checkup? (A well-baby checkup is a regular health visit for your baby usually at 2, 4, & 6 months of age.)

- ☐ No
- ☐ Yes (skip to question 58)
- ☐ Don't know/refused (circle one)

57. Did any of these things keep ___ from having a well-baby checkup? Check all that apply:

- ☐ I didn't know my baby needed one
- ☐ I didn't have enough money or insurance to pay for it
- ☐ I had no way to get my baby to the clinic or office
- ☐ I didn't have anyone to take care of my other children
- ☐ I couldn't get an appointment
- ☐ My baby was too sick to go for routine care
- ☐ Other
- ☐ Refused

58. When ___ was at home with you, did he/she develop any of the following problems or illnesses? (Do not include problems or illnesses that occurred when the baby was in the hospital). Answer no, yes, or don't know/refused. (circle one)

- ☐ Yes ☐ No ☐ Ref Cold
- ☐ Yes ☐ No ☐ Ref Fever
- ☐ Yes ☐ No ☐ Ref Eye infection
- ☐ Yes ☐ No ☐ Ref Ear infection
- ☐ Yes ☐ No ☐ Ref Vomiting
- ☐ Yes ☐ No ☐ Ref Diarrhea
- ☐ Yes ☐ No ☐ Ref Injury (specify):_____
- ☐ Yes ☐ No ☐ Ref Other illness (specify):_____

59. When ___ was sick were you able to take him/her for medical care when needed?

- ☐ All of the time
- ☐ Most of the time
- ☐ No
- ☐ Don't remember/refused (circle one)

60. Where did you take ___ when he/she was sick and in need of medical care (e.g. emergency room, clinic, primary care physician)?

61. Have you ever had a problem paying for medical care when ___ was sick?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused (circle one)

62. How did you pay for the _____ medical care (include both sick and well baby care)?

- ☐ Health insurance or HMO (including insurance from your work or your husband's work)
- ☐ Indian Health Service
- ☐ Medicaid, Medical Assistance, or MinnesotaCare
- ☐ Personal income (cash, check, or credit card)
- ☐ Tribal Health Service
- ☐ Other
- ☐ Don't know/refused (circle one)

63. After ___ came home, did you receive help or support from any program or organization? Check all that apply:

- ☐ Mental health service
- ☐ Program for children with special health needs
- ☐ Respite/day care
- ☐ Financial planning
- ☐ Genetic evaluation/counseling
- ☐ Family planning
- ☐ WIC
- ☐ Housing authority
- ☐ Group shelters
- ☐ Nurse Home Visit
- ☐ Medicaid
- ☐ Chemical health services
- ☐ Employment office
- ☐ Child protective services
- ☐ Ongoing social work case management
- ☐ Smoking cessation program
- ☐ Other (ECFE, Way to Grow, Healthy Start—specify): _____

64. Is there anything else you would like to tell me about ___'s health?

65. Were you satisfied with care ___ received at the clinic or hospital (i.e. clinic hospital, nursing visits, etc.)

Part D – Other Babies

66. Have you had any pregnancies besides the pregnancy with ___?

☐ No
☐ Yes
☐ Don't know/refused (circle one)
If yes, how many other pregnancies have you had? _____
Indicate date and outcomes for previous pregnancies (if any):

Date	Outcome (miscarriage, live birth, stillborn, abortion)

If more than four, note information on back of this page

67. Is there anything else you would like to share regarding other pregnancies?

68. Currently pregnant? (Due date_____)

Part E – Information On Mother

69. What is the highest grade/year of school or college had you completed when ___ was born?

☐ 0-11 years of school
☐ 12 years of school
☐ 13-14 years of school
☐ 15-16 years of school
☐ 17+ years of school
☐ Don't know/refused (circle one)

70. Were you employed at any time *during your pregnancy with* ___?

☐ No (skip to question 83)
☐ Yes
☐ Don't know/refused (circle one)

If yes, did you work anytime during (indicate "yes", "no" or refused)

☐ Yes ☐ No ☐ Ref First three months of pregnancy
☐ Yes ☐ No ☐ Ref Second three months of pregnancy
☐ Yes ☐ No ☐ Ref Third three months of pregnancy
☐ Yes ☐ No ☐ Ref Don't know/refused

71. Please describe what you did at your job:

72. From your perspective, were you working in a stressful environment?

☐ No
☐ Yes (please explain):

73. Did you work with potentially hazardous or harmful items such as blood, chemicals, toxic fumes, smoke, dust, or lead?

☐ No
☐ Yes (explain):
☐ Don't know/refused (circle one)

74. Were you required to use protective clothing/equipment on your job for *self-protection*?

☐ No
☐ Yes
☐ Don't know/refused (circle one)

75. How did you usually get to work?

☐ Car
☐ Taxi
☐ Bus
☐ Walked
☐ Other (specify): _____
☐ Don't know/refused (circle one)

76. How long did it take to get to work?

_____ Hours/Minutes
☐ Don't know/refused (circle one)

77. Was it difficult to get to work?

☐ No
☐ Yes
☐ Don't know/refused (circle one)

If yes, please explain:

78. Did you stop work before your delivery?

☐ No
☐ Yes
☐ Don't know/refused (circle one)

79. Did you get maternity leave?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused

80. If yes, was the leave

- ☐ Paid
- ☐ Unpaid
- ☐ Don't know/refused (circle one)

81. Were you advised to stop working by your doctor or nurse midwife?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused (circle one)

82. If yes, were you able to stop working?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused (circle one)

If no, what were the reasons you could not stop working (check all that apply)?

- ☐ I could not afford to
- ☐ My partner/family did not want me to stop
- ☐ I did not want to stop working
- ☐ I would have been fired
- ☐ I had no maternity leave
- ☐ Other (specify):

83. Is there anything else you would like to tell me about your activities or other questions in this part?

Part F – Information on Father

84. Which one of these groups best describes the racial/cultural background of the baby's father?

- ☐ American Indian
- ☐ White
- ☐ African American
- ☐ Asian (specify): _____ ☐

Other (specify): _____

85. Is the baby's father Spanish, Hispanic, or Latino

- ☐ No (skip to question 86)
- ☐ Yes
- ☐ Don't know/refused

If yes, which one of these groups' best describes the ethnicity of the baby's father?

- ☐ Mexican, Mexican American, Chicano
- ☐ Puerto Rican
- ☐ Other Spanish/Hispanic (specify):
- ☐ Cuban
- ☐ Central or South American

86. Father's Age at the time of ___ birth
_____ Years

87. What is the highest grade/year of school or college that the baby's father had completed when ___ was born?
- ☐ 0-11 years of school
- ☐ 12 years of school
- ☐ 13-14 years of school
- ☐ 15-16 years of school
- ☐ 17+ years of school
- ☐ Don't know/refused (circle one)

88. How would you describe your relationship with the baby's father during your pregnancy with ___?

- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know/refused (circle one)
- ☐ FOB was not around

89. How would you describe your relationship with the baby's father after ___ was born?

- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know/refused (circle one)
- ☐ FOB was not around

90. Was the father of the baby employed at any time *during your pregnancy with* ___?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused (circle one)

Please describe what the baby's father did at his job:

91. Was the baby's father required to use protective clothing/equipment on the job for *self-protection*?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused (circle one)

92. How satisfied were you with the FOB's contribution(s) toward your financial support?

- ☐ Satisfied
- ☐ Somewhat Satisfied
- ☐ Not Satisfied
- ☐ Unsure
- ☐ Not applicable
- ☐ Don't know/refused (circle one)

93. During your pregnancy, did the baby's father have any of the following:

- ☐ Work, employment problems or lost job
- ☐ Money problems
- ☐ Emotional or mental health problems
- ☐ Problems with children or other relative
- ☐ Problems with the law or incarceration
- ☐ Health problems or hospitalization
- ☐ Violence or abuse
- ☐ Problems with drugs or alcohol
- ☐ Housing problems
- ☐ A death in the family
- ☐ None
- ☐ Other (specify): _____

94. Is there anything else you would like to tell me about ___'s father?

Probes
Did he attend classes, attitude about baby, relationship now?

Part G – Living Situation

In this section, we would like to find out about your living situation during your pregnancy and before ___ died.

95. What were the sources of your household's income? Check all that apply

- ☐ Paycheck or money from a job
- ☐ Money from family or friends
- ☐ Money from a business, fees, dividends, or rental income
- ☐ Aid such as MFIP, Temporary Assistance for Needy Families (TANF), welfare, WIC, public assistance, general assistance, food stamps, or Supplemental Security Income
- ☐ Unemployment benefits
- ☐ Child support or alimony
- ☐ Social security, workers' compensation, disability, veteran benefits, or pensions
- ☐ Refused
- ☐ Other

96. Please tell us: What was your total household income before taxes? Include your income, your husband's or partner's income, and any other income you may have used. (All information will be kept private and will not affect any services you are now getting.) Check one answer

- ☐ Less than $10,000
- ☐ $10,000 to $14,999
- ☐ $15,000 to $19,999
- ☐ $20,000 to $24,999
- ☐ $25,000 to $34,999
- ☐ $35,000 to $49,999
- ☐ $50,000 or more

97. How many people, including yourself, depended on this income?

_____ People

98. Did you rent or own?

- ☐ Rent
- ☐ Own
- ☐ NA, living with family, in-laws, or friends
- ☐ Refused

99. Do you feel you had enough room for ___?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused

100. Did you move your residence when you were pregnant with ___

- ☐ No
- ☐ Yes (indicate # of times)
- ☐ Don't know/refused (circle one)

101. Did you move your residence after ___ was born?

- ☐ No
- ☐ Yes (indicate # of times)
- ☐ Don't know/refused (circle one)

102. How did you feel about your overall living situation?

- ☐ Satisfied
- ☐ Dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Don't know/refused (circle one)

103. Is there anything else you would like to tell me about your living situation?

Part H – Life Changes/Social Supports

Pregnancy can be a difficult time for some women. The next questions are about some things that may have happened to you during your pregnancy and before ___ died.

Interviewer Note: Skip to Question 107 *if husband or FOB is present and mother may be uncomfortable answering.*

104. For each item, tell me "Yes" if it happened to you and "No" if it did not. Remember, this is during your pregnancy and before ___ died. Remember you can ask that we skip any question at any time.

☐ Yes ☐ No A close family member had health problems or went to the hospital
☐ Yes ☐ No A close family member had emotional or mental health problems
☐ Yes ☐ No You got separated or divorced from your husband or partner
☐ Yes ☐ No You were homeless
☐ Yes ☐ No You had a lot of bills you couldn't pay
☐ Yes ☐ No You lost your job even though you wanted to continue working
☐ Yes ☐ No You and your husband or partner argued more than usual
☐ Yes ☐ No Your husband or partner did not want you to be pregnant
☐ Yes ☐ No You had problems with children or other relatives
☐ Yes ☐ No You were involved in a physical fight
☐ Yes ☐ No You or your husband or partner had problems with the law or went to jail
☐ Yes ☐ No You or someone very close to you had problems with drugs or alcohol
☐ Yes ☐ No Someone very close to you died
☐ Yes ☐ No You were afraid of violence in your neighborhood

The next questions are about any hitting, pushing, slapping, kicking, etc that went on during your pregnancy and afterward.

105. While your were pregnant with ___, did any of the following people push, hit, slap, kick, choke, or physically hurt you in any other way? Indicate "Yes" or "No". You can refuse to answer or ask to skip the question.

☐ Yes ☐ No No one physically abused me
☐ Yes ☐ No My husband or partner
☐ Yes ☐ No A family or household member other than my husband or partner
☐ Yes ☐ No A friend
☐ Yes ☐ No A supervisor or co-worker
☐ Yes ☐ No Someone else
☐ Yes ☐ No Don't know/refused

106. After ___'s delivery, did any of the following people push, hit, slap, kick, choke, or physically hurt you in any other way? Indicate "Yes" or "No". You can refuse to answer or ask to skip the question.

☐ Yes ☐ No No one physically abused me
☐ Yes ☐ No My husband or partner
☐ Yes ☐ No A family or household member other than my husband or partner
☐ Yes ☐ No A friend
☐ Yes ☐ No A supervisor or co-worker
☐ Yes ☐ No Someone else
☐ Yes ☐ No Don't know/refused

107. When you were pregnant with ___, who would have helped you if a problem came up? (For example, who would help you if you needed to borrow $50 or if you got sick and had to be in bed for several weeks?)

☐ My husband or partner
☐ My mother, father, or in-laws
☐ Other family member or relative
☐ A friend
☐ Someone else
☐ No one would help me
☐ Refused

108. Since you delivered ___ and prior to his/her death, who would have helped you if a problem came up? (For example, who would help you if you needed to borrow $50 or if you got sick and had to be in bed for several weeks?)

☐ My husband or partner
☐ My mother, father, or in-laws
☐ Other family member or relative
☐ A friend
☐ Someone else
☐ No one would help me
☐ Refused

109. During your pregnancy with ___, how often did you feel down, depressed, or hopeless?

☐ Always
☐ Often
☐ Sometimes
☐ Rarely
☐ Never
☐ Refused

110. During your pregnancy with ___, how often have you felt little interest or little pleasure in doing things?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Refused

111. After ___ was born and prior to his/her death, how often did you feel little interest or little pleasure in doing things?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Refused

112. After ___ was born and prior to his/her death how often did you feel down, depressed, or hopeless?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Refused

113. Since the death of ___ did you receive counseling or join a support group for parents who have lost a baby?

- ☐ No
- ☐ Yes
- ☐ Don't know/refused

114. Who did you go to for counseling (e.g. physician, clergy, therapist)?

I've been asking a lot of specific questions. Now I would like you to respond in your own words to these more general questions. I will record your responses but will turn off the tape recorder at any time you wish.

(TURN ON THE TAPE RECORDER)

115. What was it that got you through the first days or weeks after ___ died?

☐ Don't know
☐ Refused

Probes
What was the biggest help or comfort to you?
What were some of the feelings you went through?
Who, if anyone, could you really talk to?
Who, if anyone, is there for you now?

116. What advice do you have for families experiencing the death of their baby?

117. What advice do you have for others, such as relatives, friends, neighbors, people at work, and so on?

118. What advice do you have for the heath care system and other providers of services (e.g. hospitals, clinics, doctors, nurses, EMS, coroners/medical examiners, funeral home directors, law enforcement, social workers, clergy, counselors, health plans, insurance)

Probes
During your pregnancy?
During your labor, delivery, and hospital stay?
During ___'s life?
During the period around the time of ___'s death
During the period after ___'s death,; during your grief?

119. What advice do you have for programs for families in your community?

End: THANK YOU for taking the time to participate in this interview. Do you have any questions for me?

120. Is there any else you would like to add?

(TURN OFF THE TAPE RECORDER)

Interview Observations/Notes (To be completed after leaving interview site)

1. Who was the primary participant in the interview?

   ☐ Mother of infant
   ☐ Other (Specify): _____

2. Did the participant have any difficulty hearing the questions?

   ☐ No
   ☐ Yes
   ☐ Don't know/refused

   If yes, describe:

3. Did the participant have any difficulty understanding the questions?

   ☐ No
   ☐ Yes
   ☐ Don't know/refused

   If yes, describe:

4. Did the participant have any difficulty reading the consent?

   ☐ No
   ☐ Yes
   ☐ Don't know/refused

   If yes, describe:

5. What was the participant's attitude about being interviewed *at the beginning of the interview?*

   ☐ Very interested/enthusiastic
   ☐ Somewhat interested/enthusiastic
   ☐ Indifferent
   ☐ Somewhat reluctant

6. What was the participant's attitude about being interviewed *during the interview?*

   ☐ Very interested/enthusiastic
   ☐ Somewhat interested/enthusiastic
   ☐ Indifferent
   ☐ Somewhat reluctant

7. Were there any sections or questions that seem to upset or irritate the participant?

   ☐ No
   ☐ Yes (specify pages and/or questions)

8. Other comments:

9. How long did the interview take? How long did the total visit or visits take?

10. Was anyone else present during the interview?

☐ No
☐ Yes

If yes, who else was present:

11. Do you think the respondent might have answered differently because of others that were present?

☐ No
☐ Yes
If yes, describe:

Indicate here referrals that you made as a result of visits with this family. Also indicate here if visits with this family identified the need for referral resources or community resources not currently available.

Note any additional comments or observations here.

Appendix C:
Project Consents

AMERICAN INDIAN INFANT MORTALITY REVIEW

Informed Consent to Participate

(Note to Interviewer: please initial each box as information is discussed with the mother)

You are invited to participate in an infant death research project sponsored by the Minnesota Department of Health.

☐ The purpose of this study is to provide information about the circumstances surrounding the deaths of American Indian babies in Minnesota so that we may better understand how to reduce the number of deaths in the future.

☐ You will be asked questions about your experiences before, during, and after your baby's death and some questions about the baby's father. This interview will take 1 to 2 hours. All information collected will be kept confidential by project staff. Information that could identify any parent, baby, health care worker or health facility will not be released to anyone except those persons working directly with the project. Those individuals will sign a confidentiality agreement before beginning work on the project. Reports that may result from this project will contain summary information only, not individual information.

☐ With your consent, the interviewer will record questions at the beginning and end of the interview. The tape of this portion of the interview and the paper copy of the remainder of the interview will be kept private under lock and key until the project is completed. Your name will not be on the tape or on the paper interview. Your interview information will be identified by a numerical code. When the project is completed, all information will be destroyed.

☐ You will be asked to provide permission for the project staff to review the medical records related to your pregnancy, delivery, and the baby's health and death.

☐ Risks involved in participating in this interview include:

Emotional distress from re-visiting and talking about the death of your infant. The interviewer is mandated by law to report any evidence of child abuse or neglect, if observed or learned during the interview.

☐ Benefits as a result of participating in this interview include:

You may find it healing to talk about your infant with someone.
This research may lead to a reduction in American Indian infant deaths.
To thank you for participating you will receive two $50.00 gift cards.

☐ You do have the right to decline to provide this information, either by declining to do the interview entirely, or by declining to answer one or more questions during the interview. You may also decline to have your interview recorded. Your right to do this will be respected at all times.

☐ If you choose not to participate in some or all of the interview, you will not be penalized in any way. Declining to participate will not affect your right, or your family's right, to receive services or benefits to which you are entitled, now or in the future.

☐ If you have questions or want addititional information about this project, please contact Cheryl Fogarty, Infant Mortality Consultant, Minnesota Department of Health at 651-201-3740.

☐ If you have questions about your rights as a research subject, please contact Pete Rode, Administrator of the Minnesota Department of Health Institutional Review Board, at 651-201-5942.

I understand the above information, and I agree to be interviewed for the American Indian Infant Mortality Review Project.

Mother's signature: _____

Witness signature: _____(Interviewer)

Date: _____

Authorization to Release Information to the Minnesota Department of Health - Mother

Patient Name:_____ Date of Birth: _____

Name of health care provider(s): _____

_____

Name of clinic(s)/hospital: _____

_____

_____

Information to be released. I give my permission for the healthcare provider(s) listed above to release to the Minnesota Department of Health, Maternal & Child Health Section the following information about me:

> My prenatal care, labor & delivery, postpartum care, and discharge summary for my pregnancy ending in the birth of my baby (name):_____ _____born (date)_____

Purpose. The Minnesota Department of Health will use this information to conduct a review of American Indian infant deaths to determine what factors/conditions contributed to my baby's death in order to prevent future deaths of infants. If the results of the study are published or reported, they will be published or reported as a summary. My identity and my baby's identity will not be known.

Privacy protections; redisclosure. At the hospital or clinic and at my health care provider's office, my health information is protected by federal and state medical privacy rules. After the information is disclosed to the Minnesota Department of Health, the information will be protected by the Minnesota Government Data Practices Act. Under that Act, my health information is private. Minnesota Department of Health staff will have access to the information to the extent needed to perform the review described above. The Minnesota Department of Health will not release identifying information to any unauthorized person without my permission.

Right to refuse; right to cancel. I understand that I do not have to agree to the release of information described in this document, and I may cancel my permission at any time. In order to cancel my permission, I need to send or deliver a letter to Cheryl Fogarty, Minnesota Department of Health, Maternal & Child Health Section, 85 E. 7th Place St. Paul, MN 55101, and include in the letter my request that my permission be cancelled, my name and date of birth, and my signature. I also understand refusing to sign this permission will not affect the current or future care I receive at the hospital or clinic named above, or receive from any other health care provider, and will not cause any penalty or loss of benefits to which I am otherwise entitled.

Expiration. This permission will expire on _____ (one year from the day it was signed). However, medical records can only be released regarding the time period listed above and for the reasons listed above. No other parts or time periods of the medical record can be released. If I sign this permission, I understand that the Minnesota Department of Health will provide a copy of this consent form to me.

Signature _____ Date: _____

Note to health care providers: This document complies with the requirements of HIPAA (the Health Insurance Portability and Accountability Act), the Minnesota Government Data Practices Act, and the Minnesota Health Records Act, regarding authorizations to disclose protected health information. See 45 C.F.R. § 164.508(c); Minn. Stat. §§ 13.05, subd. 4(d), 144.335, subd. 3a.

Authorization to Release Information to the Minnesota Department of Health - Parent/Guardian

Baby's Name:_____ Date of Birth: _____

Name of Parent/Guardian:_____

Name of health care provider(s): _____

_____

Name of clinic/hospital(s): _____

_____

_____

Information to be released. I give my permission for the healthcare provider(s) listed above to release to the Minnesota Department of Health, the following information about my child:

> My baby's health care records including care at birth, nursery or newborn intensive care, discharge summary, follow up well and/or sick baby care, emergency care, additional hospitalizations, and the autopsy report.

Purpose. The Minnesota Department of Health will use this information to conduct a review of American Indian infant deaths to determine what factors/conditions contributed to my baby's death in order to prevent future deaths of infants. If the results of the study are published or reported, they will be published or reported as a summary. My identify and my baby's identity will not be known.

Privacy protections; redisclosure. At the hospital or clinic and at my child's health care provider's office, my child's health information is protected by federal and state medical privacy rules. After the information is disclosed to the Minnesota Department of Health, the information will be protected by the Minnesota Government Data Practices Act. Under that Act, my child's health information is private. Minnesota Department of Health staff will have access to the information to the extent needed to perform the research described above. The Minnesota Department of Health will not release identifying information to any unauthorized person without my permission.

Right to refuse; right to cancel. I understand that I do not have to agree to the release of information described in this document, and I may cancel my permission at any time. In order to cancel my permission, I need to send or deliver a letter to Cheryl Fogarty, Minnesota Department of Health, Maternal & Child Health Section, 85 E. 7th Place, St. Paul, MN 55101, and include in the letter my request that my child's permission be cancelled, my name, my child's name and date of birth, and my signature.

Expiration. This permission will expire on _____(one year from the day it was signed). However, medical records can only be released regarding the time period listed above and for the reasons listed above. No other parts or time periods of the medical record can be released. If I sign this permission, I understand that the Minnesota Department of Health will provide a copy of this consent form to me.

Signature of Parent/Guardian _____ Date: _____

Note to health care providers: This document complies with the requirements of HIPAA (the Health Insurance Portability and Accountability Act), the Minnesota Government Data Practices Act, and the Minnesota Health Records Act, regarding authorizations to disclose protected health information. See 45 C.F.R. § 164.508(c); Minn. Stat. §§ 13.05, subd. 4(d), 144.335, subd. 3a

American Indian Infant Mortality Review (IMR)
Case Review Team Member
Data Confidentiality Agreement

As a member of the Case Review Team (CRT), **I understand and agree:**

1. That each infant death case summary has been prepared for the purposes of:
   a. identifying factors that contribute to poor pregnancy outcomes; and
   b. developing recommendations to improve the medical, health, and social systems that provide services and support to women, infants, and families in our community

   The use of any information in any case summary **for any other purpose is prohibited by Minnesota law.**

2. That the collection, maintenance, and use of all data on individuals in each case summary are governed by the *Minnesota Government Data Practices Act (Minnesota Statutes,* Section 13.01-13.90) and by *Minnesota Rules* implementing the Act. **No data or information contained in any case summary or any team discussion of any case summary will be discussed by me with anyone outside the Case Review Team meeting,** either during my period of service on the CRT or thereafter.

3. That, if I believe that I recognize a particular individual, facility, or agency from anything mentioned in any case summary, **I will not disclose the identity** of that individual, facility, or agency to any other person during or outside the CRT meeting.

4. That **I will return** each case summary that I review to the CRT facilitator after the death has been reviewed.

_____
American Indian IMR Project, Case Review Team Member Signature

_____
Date

American Indian Infant Mortality Review (IMR) Project
Maternal Interviewer
Data Confidentiality Agreement

As a Project Maternal Interviewer, **I understand and agree:**

1. That all information I collect from the mothers whose babies died has been collected for the purposes of:
   a. identifying factors that contribute to poor pregnancy outcomes; and
   b. developing recommendations to improve the medical, health, and social systems that provide services and support to women, infants, and families in our community

   The use of any information collected **for any other purpose is prohibited by Minnesota law.**

2. That, the collection, maintenance, and use of all data on individuals for each infant death case are governed by the *Minnesota Government Data Practices Act (Minnesota Statutes,* Section 13.01-13.90) and by *Minnesota Rules* implementing the Act. **No data or information collected during the maternal interview will be discussed or disseminated by me with anyone except the project coordinator and/or the principal investigator,** either during my period of service or thereafter.

3. That, **I will not disclose the identity** of any individual, facility, or agency to any other person except the project coordinator and/or the principal investigator.

4. That, **I will deliver all taped and written information obtained from the maternal interview to the project coordinator and/or principal investigator as soon as it is obtained and will not retain copies of any collected information.**

_____
American Indian IMR Project, Maternal Interviewer Signature

_____
Date

American Indian Infant Mortality Review (IMR) Project
Case Summary Writer
Data Confidentiality Agreement

As a Project Case Summary Preparer, **I understand and agree:**

1. That all information I summarize from the medical records, maternal interviews, birth and death certificates, and other public data sources of mothers and infants in the event of an infant death has been summarized for the purposes of:
   a. identifying factors that contribute to poor pregnancy outcomes; and
   b. developing recommendations to improve the medical, health, and social systems that provide services and support to women, infants, and families in our community

   The use of any information collected and summarized **for any other purpose is prohibited by Minnesota law.**

2. That, the collection, maintenance, and use of all data on individuals in each infant death case are governed by the *Minnesota Government Data Practices Act (Minnesota Statutes,* Section 13.01-13.90) and by *Minnesota Rules* implementing the Act. **No data or information reviewed and summarized will be discussed or disseminated by me with anyone except the project coordinator and/or the principal investigator,** either during my period of service or thereafter.

3. That, **I will not disclose the identity** of any individual, facility, or agency to any other person except the project coordinator and/or the principal investigator.

4. That, **I will deliver all source documents obtained and summarized and the completed summary to the project coordinator and/or principal investigator as soon as it is completed and will not retain copies of any collected information.**

_____
American Indian IMR Project, Case Summary Writer's Signature

_____
Date

American Indian Infant Mortality Review (IMR) project
Medical Records Abstractor
Data Confidentiality Agreement

As a Project Medical Records Abstractor, **I understand and agree:**

1. That all information I collect from the medical records of mothers and infants in the event of an infant death has been collected for the purposes of:
   a. identifying factors that contribute to poor pregnancy outcomes; and
   b. developing recommendations to improve the medical, health, and social systems that provide services and support to women, infants, and families in our community

   The use of any information collected **for any other purpose is prohibited by Minnesota law.**

2. That, the collection, maintenance, and use of all data on individuals in each infant death case are governed by the *Minnesota Government Data Practices Act (Minnesota Statutes,* Section 13.01-13.90) and by *Minnesota Rules* implementing the Act. **No data or information collected during the medical records abstracting will be discussed or disseminated by me with anyone except the project coordinator and/or the principal investigator,** either during my period of service or thereafter.

3. That, **I will not disclose the identity** of any individual, facility, or agency to any other person except the project coordinator and/or the principal investigator.

4. That, **I will deliver all written information obtained from the medical records abstracting to the project coordinator and/or principal investigator as soon as it is obtained and will not retain copies of any collected information.**

_____
American Indian IMR Project, Medical Records Abstractor Signature

_____
Date

American Indian Infant Mortality Review (MR) Project
Maternal Interview Transcriptionist
Data Confidentiality Agreement

As the Project Transcriptionist, **I understand and agree:**

1. That all information collected from the mothers whose babies died has been collected for the purposes of:
   a. identifying factors that contribute to poor pregnancy outcomes; and
   b. developing recommendations to improve the medical, health, and social systems that provide services and support to women, infants, and families in our community

   The use of any information collected **for any other purpose is prohibited by Minnesota law.**

2. That, the collection, maintenance, and use of all data on individuals for each infant death case are governed by the *Minnesota Government Data Practices Act (Minnesota Statutes,* Section 13.01-13.90) and by *Minnesota Rules* implementing the Act. **No data or information collected during the maternal interview and transcribed by me will be discussed or disseminated by me with anyone except the project coordinator and/or the principal investigator,** either during my period of service or thereafter.

3. That, **I will not disclose the identity** of any individual, facility, or agency to any other person except the project coordinator and/or the principal investigator.

4. That, **I will deliver all taped and transcribed information obtained from the maternal interview to the project coordinator and/or principal investigator as soon as it is transcribed and will not retain copies of any collected information.**

_____
American Indian IMR Project, Maternal Interview Transcriptionist Signature

_____
Date

Appendix D:
Case Review Team Worksheet

American Indian Case Review TeamWorksheet

Case ID#:_____
Date of Review:_____

A. Identification of Significant Issues and Contributing Factors

1. Service Delivery Systems:

2. Parent/Family:

3. Interface Between Parent(s) and Service Delivery System:

4. Community/Environment:

5. Other:

Case ID#_____
Date of Review_____

B. What are the Most Significant Issues and Factors Identified?

Issues or Factors (summarize)	Modifiable? (yes/no)	If yes, in what way?	Recommendations

Appendix E:
Definitions of Levels of Hospital Perinatal Care

Capabilities of Providers in Hospitals Delivering Basic, Specialty, And Subspecialty Care[1]

Level of Care	Capabilities	Provider Types
Level I (basic)	Surveillance and care of all patients admitted to the obstetric service, with an established triage system for identifying patients at high risk who should be transferred to a facility that provides specialty or subspecialty care Proper detection and initial care of unanticipated maternal-fetal problems that occur during labor and delivery Capability to begin an emergency cesarean delivery within 30 minutes of the decision to do so Availability of appropriate anesthesia, radiology, ultrasonography, and laboratory and blood bank services on a 24-hour basis Care of postpartum conditions Resuscitation and stabilization of all neonates born in the hospital Evaluation and continuing care of healthy neonates in a nursery or with their mothers until discharge Adequate nursery facilities and support for stabilization of small or ill neonates before transfer to a speciality or subspecialty facility Consultation and transfer arrangements Accommodations and policies that allow families, including their other children, to be together in the hospital following the birth of an infant Data collection, storage, and retrieval Quality improvement programs, including efforts to maximize patient safety	Family physicians, obstetricians, pediatricians

Level of Care	Capabilities	Provider Types
Level II (specialty)	Provision of basic care services as described previously and, in addition, provision of the following enhanced services: • Care of appropriate women at high risk and fetuses, both admitted and transferred from other facilities • Stabilization of severely ill newborns before Transfer • Treatment of moderately ill, larger preterm and term newborns	Obstetricians, pediatricians, sometimes neonatologists
Level III (subspecialty)	Provision of comprehensive perinatal health care services for both directly admitted and transferred women and neonates of all risk categories, including basic and speciality care services as described previously Evaluation of new technologies and therapies	Maternal-fetal medicine specialists, neonatologists
Regional subspeciality perinatal health care center	Provision of comprehensive perinatal health care services organization and coordination, including the following areas: • Maternal and neonatal transport • Regional outreach support and education • Development and initial evaluation of new technologies and therapies • Training of health care providers with specialty and subspecialty qualifications and capabilities • Analysis and evaluation of regional data, including those on perinatal complications and outcomes	Maternal-fetal medicine specialists, neonatologists, other subspecialists, including obstetric, pediatric, and surgical subspecialists

[1]American Academy of Pediatrics & American College of Obstetricians & Gynecologists. *Guidelines for Perinatal Care, 6th Edition.* 2007; 11-12.

Appendix F:
Causes & Timing of Deaths Not Reviewed

Causes and Timing of Death for the Seven Deaths Not Reviewed

The project had vital records data on seven additional deaths of the 31 deaths identified for the 2005-2006 period. Two of these infants died of SIDS. One of the two SIDS deaths occurred at four months of age and was called “probable SIDS” with no contributing conditions listed. The other death was called “SIDS” but the manner of death could not be determined because contributing conditions stated “suffocation by overlaying parent could not be ruled out”. This infant was 3-1/2 months old at death.

The third case was a death of a full term normal weight infant who suffered severe intra-partum asphyxia when induction of labor failed and the fetal heart stopped. The infant was delivered by Caesarean section and lived for five days.

The remaining four deaths were from birth defects: three were heart defects, and one was a severe neural tube defect. These four deaths raised the total of American Indian babies dying from birth defects to eight (26 percent) for the period 2005-2006.

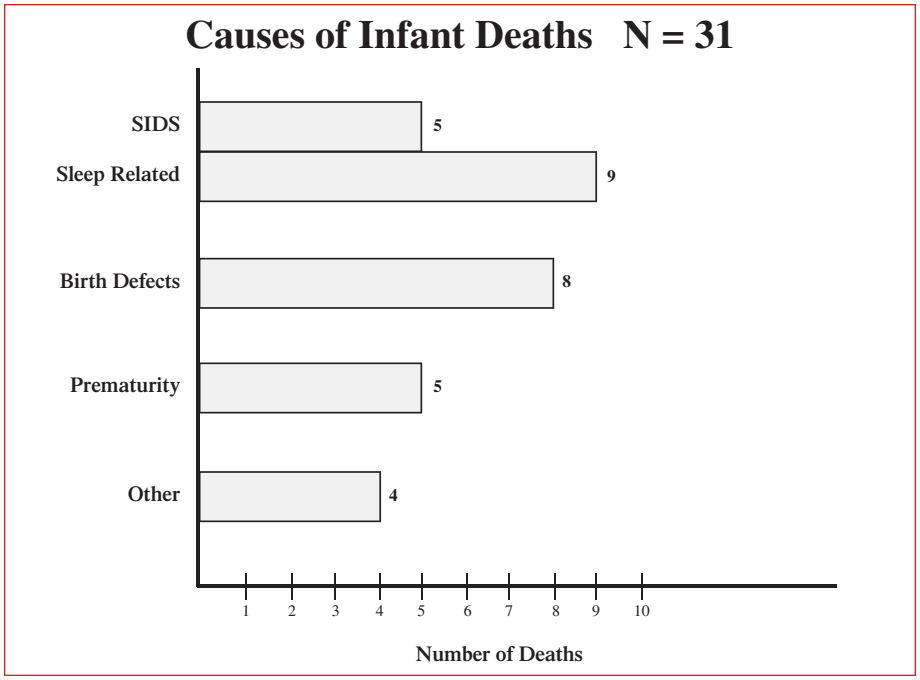
Of these seven additional mothers, two used tobacco, one used cocaine, one used marijuana, and none used alcohol, according to birth certificate data.

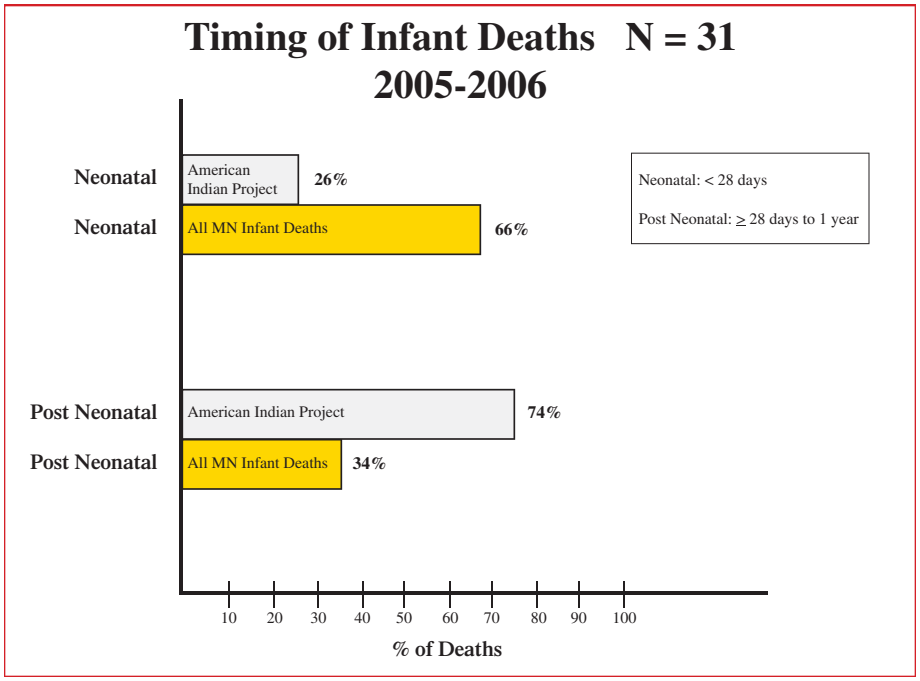
Had the CRT reviewed these seven additional deaths, there would be two more neonatal deaths for a total of eight (26 percent) and five more post neonatal deaths for a total of 23 (74 percent). There would be 14 sleep-related deaths (45 percent) and eight deaths from birth defects (26 percent) which include six babies with heart defects and two with neural tube defects. Birth defects would then be the second highest cause of death for the population of 31 American Indian infant deaths from the two-year period, 2005-2006.

The seven deaths not reviewed by the CRT did not add to the number of premature births. One baby, however, born at 38 weeks gestation, was low birth weight at 3 pounds 8 ounces.

Of these seven non-reviewed deaths, two mothers had adequate prenatal care and five did not. Combined with the 24 reviewed cases, 13 of 31 mothers had early and adequate prenatal care (42 percent).

These seven mothers’ ages ranged from 19 to 27 with six mothers in their twenties, one mother age 19. Education levels ranged from 11th grade (3 mothers) and 12th grade (2 mothers) to college educated (2 mothers). Five mothers were American Indian and two were white. Both of the babies born to white mothers were listed as American Indian (one was mixed race) on the death certificates.





Why discuss the seven cases not reviewed?

Adding the information on the seven cases not reviewed means that this report can comment on the whole population of American Indian infant deaths that occurred during the 2005-2006 period. The American Indian infant mortality rate, as previously stated, has been two to three times the White rate since infant mortality rates by race/ethnicity have been measured in Minnesota. Each death is a tragedy for the family, the population and for Minnesota. All available information that can shed light on the issues and lead to the elimination of this health disparity should be included.

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