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Causes of Native American infant mortality.

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I. Introduction

Although dramatic gains have been realized in lowering the incidence of neonatal deaths among native American infants to a level lower than the white race, postneonatal death rates for this population remain almost twice as high as in the white race. The limited data available reveal that excessive postneonatal deaths among native American infants largely result from SIDS, preventable accidents and treatable acute medical conditions, such as pneumonia and gastroenteritis. This suggests that native American infants leave the hospital healthy but go to unsafe environments, which decrease their chances of survival past one year.

The American Academy of Pediatrics has undertaken a four-year project to address the excessive rate of postneonatal death among native American infants. In four Indian Health Service (IHS) Areas, extensive data on postneonatal deaths occurring between 1986 and 1988 were collected and analyzed to determine causes of and circumstances surrounding the infant deaths. Panels of pediatric experts were convened in each Area to review data and meet with community health leaders to plan intervention programs. The interventions are carried out by the local community and the Area IHS program, with continued monitoring by the Project Staff. The goal of the Project is to gain an understanding of postneonatal deaths among Indian infants that can be used to
develop effective health policy interventions. The project attempted to involve the native American community in the development and implementation of health programs that can help to decrease mortality for native American infants.

II. Data Collection

Birth certificate, death certificate, and medical record information was collected on all native infant deaths in four Indian Health Service Areas, Aberdeen, Alaska, Billings and Portland for 1986-1988. The states included in the four Areas are, Alaska, Washington, Oregon, Idaho, Montana, Wyoming, North Dakota, South Dakota, Iowa and Nebraska. Information from native infant deaths recorded in 1986, 1987 and 1988 was retrieved from state health departments, hospitals, and IHS records when available.

Tallies of the number of neonatal and postneonatal deaths for each study Area for each year are reported in Table 1. Neonatal deaths are those that occurred in the first 28 days of life, and postneonatal deaths are those that occurred in days 29 through 364. A total of 463 native infant deaths were recorded for the four Areas. In each Area, and for each of the years 1986 to 1988, the rate of postneonatal death exceeds the neonatal death rate. When compared to the number of neonatal deaths, postneonatal deaths vary from almost equal to twice as frequent over the three year
period. These rates and ratios confirm the Project's premise that native American infants disproportionately die in the postneonatal period.

Project data permitted us to examine the causes of neonatal and postneonatal death for 1986, 1987 and 1988 in the four Project sites. Results are reported in Figure 1, where they are compared to causes of death for all infants in the U.S. Causes of death are grouped similarly to reports from the National Center for Health Statistics. Most noteworthy is that for congenital anomalies only, total U.S. and American Indian rates are similar. In all other categories, and especially for SIDS, Indian infants are at higher risk.

Figure 2 depicts the distribution of postneonatal deaths for the study Areas. Most noteworthy is that 49% are attributed to SIDS. This compares to 30% of postneonatal deaths for all races (Figure 3.)

In these figures, deaths are categorized according to the cause of death listed on the death certificate. We note, however, that Project activities allowed us to reevaluate many postneonatal deaths with an indepth review by an expert panel, and for over one fourth of all non-SIDS deaths, death certificates were deemed inaccurate in terms of the listed cause of death.
III. Panel Process

The project convened a scientific advisory panel in each of the IHS Areas to perform indepth infant mortality reviews. Unlike traditional medical audits, which rely mainly on clinical information found in medical records, infant mortality review generally includes consideration of not only medical but socioeconomic, public health, behavioral, educational and health systems factors which may have contributed to the deaths of infants. Because infant death review searches more widely than traditional medical audits for factors which may be implicated in infant deaths, it was necessary that our team of reviewers begin the process of infant death review with an underlying framework which defined both the domains to be considered in the review process and the content encompassed within each domain. Our review team included members of different disciplines, including public health nursing, pathology, pediatrics, public health and SIDS. It was important that team members explicitly acknowledged that the review encompasses factors broader than any one individual's area of expertise, agreed on what these factors included, and abided by these domains during the review process. The process of agreeing on an underlying conceptual framework ensured that everyone around the table agreed on the meaning of various terms and attempted to apply them uniformly.
The substantial literature on factors contributing to neonatal and postneonatal mortality was used to develop the conceptual framework underlying this review. For our purposes, four domains were defined as potential contributors to infant death: community factors; parent or extended family factors; health care system factors; and medical provider factors.

A number of community factors were thought to be among possible contributors to infant deaths. These included the degree of poverty in the community and the pervasiveness of certain attitudes or norms regarding the use of health care as measured by certain key indicators or scales. Finally, evidence of the degree of tribal health program activity and policy, as well as tribal community development activity, were included among community factors.

The scientific panel agreed that the following family factors would be among those considered: various maternal characteristics; evidence of delay or failure to seek medical care; evidence of noncompliance with treatment plan; evidence of lack of knowledge regarding an important event or risk; information about the household milieu (stability of members, stability of location, presence of substance abuse, employment, adult sharing of responsibilities); and evidence of maternal or primary caretaker stress (excess
parity, recent family death, marital disputes, family illness, grandmother intercedence).

Unavailability of services, inaccessibility of services, distance to a full-service clinic, the adequacy of community health nursing coverage, as well as the mix, training, and coverage provided by IHS Service Unit personnel were among relevant health care system factors which may contribute to infant deaths. Also important are Service Unit policies which may contribute to delayed or inadequate care. These would include aspects of clinic management, accessibility of family planning, the characteristics of the referral network, aspects of pharmacy policy, as well as the degree of tribal or community input into Service Unit policies. Finally, health care system factors also included such matters as the accessibility of Medicaid eligibility to the Native American population and the health care resources available to Native Americans not residing in IHS direct or contract service areas and to those not eligible for the assistance of the Indian Health Service.

Medical care provides factors included evidence of delay in diagnosis, treatment, or follow-up; misdiagnosis; evidence of failure to refer or seek consultation; lack of treatment plans and assurance of case management; and evidence of poor communication between providers (including transmission of
discharge summaries and care plans from urban or distant medical centers to local providers).

Once this underlying conceptual framework was agreed to, the panel developed a tool to be used in summarizing findings regarding each case under review and to aggregate findings across all cases.

The infant death review form included five discrete items of information related to the cause of death. The first, recorded in item 2, indicated the cause of death as named on the death certificate. The scientific advisory committee considered it important to evaluate the named cause of death, indicate the accuracy of this information and, where the available information permitted, to indicate an amended cause of death. Thus, item 3 provided the panel the opportunity to amend the cause of death based upon their review and item 4 provided an opportunity to rate the probable accuracy of the death certificate cause of death as either of low, moderate, or high accuracy. In cases where the certificate cause of death was amended, the accuracy of the death certificate cause of death (item 4) would obviously be rated by the panel as low. However, when the panel doubted the death certificate cause of death but had insufficient information upon which to develop an amended cause of death, no amended cause of death was developed and
the accuracy score coded in item 4 would also be rated as low.

In addition to evaluating the accuracy of the cause of death as recorded on the death certificate, the panel felt it was important to make some judgment about the degree to which the cause of death was preventable and the degree of their certainty about this judgment. This information was recorded in line 6. The preventability of some causes of death were judged to be unknown. Alternatively, they were judged as either having been unpreventable, possibly preventable, or preventable. In addition, panelists were given the opportunity to indicate that they had no information upon which to make this judgment. Alternatively, if information was available, they had the opportunity to indicate a low, moderate, or high degree of certainty in making this judgment.

Most of the remaining information collected on the infant death review form summarized the panel's evaluation of the role of various factors in each infant death. Separate evaluation was made of each of the four factors named earlier: family factors, community/cultural factors, system of care factors, and provision of care factors. For each factor, a determination was first made of its overall relevance to the death; the factor was judged as either not
relevant, or of low, moderate, or high relevance. Second, a
determination was made as to whether this factor was
preventable. Third, panelists were given an opportunity to
indicate the degree of certainty about the information upon
which these judgments were made. This "certainty of
information" score was useful in explicitly recognizing the
numerous occasions on which panelists either felt that no
information was available with which to assess the role of
particular factor in an infant death, or felt that the
available information did not permit any judgment to be made
with a high degree of certainty.

The form also permitted panelists to comment on
interventions which might have ameliorated certain factors
in the infant death. This information was particularly
important in ensuring that practical recommendations for
preventing future infant deaths emerged from the review
process.

Finally, following the factor by factor evaluation of the
infant death, item 7 gave the panel the opportunity to
develop a judgment about the single most important factor in
each death. This might be the cause of death itself or,
alternatively, it might be either the family,
community/cultural, system of care, or provision of care
factor.
In recognition of the fact that Native American infants obtain health care under several different service systems, the infant death review form notes the major source of the infant's care as either having been from the Indian Health Service, from a provider under contract with the IHS, or from a non-IHS facility or provider.

The panel reviewed each infant death individually, beginning its work with a thorough review of a summary developed on each case. Following review and discussion of the case summary, the infant death review tool was completed not by individual team members, but by the team as a whole. At times, extensive discussion was necessary in order to reach agreement among team members about the coding of individual items.

Not all infant deaths were reviewed. The Project Advisory Committee delineated the following criteria for selection of deaths for review by the Panel:

1) All SIDS deaths;
2) All cases with unknown causes of death;
3) All cases with questionable causes of death;
4) No cases in which infants never left the hospital;

This yielded 305 infant deaths for Panel review over the three years of the Project. One hundred and forty-nine of these were SIDS (48%) with the remaining causes of death
distributed as described in Table 2. The reviews were done in the four Project sites and for 1986, included personnel from the local IHS and tribal health programs.

Table 3 reports the Panel's determination of how accurate the cause of death listed on the death certificate was for the 305 cases reviewed. Other than in the Aberdeen Area, just about all SIDS deaths were deemed as accurately coded on death certificates. In Aberdeen, however, the Panel learned that autopsy and pathology resources made the certain determination of SIDS difficult. Interventions were planned and instituted to address this problem. Panel members consulted with the local pathologists and health agencies to define better practices for diagnosing SIDS.

Regarding Non-SIDS deaths, Areas varied from just less than one half to over two thirds of infant deaths with low accuracy regarding the cause of death on the death certificate. This finding highlights the importance of information gathering and recording at the time of death to the proper performance of infant death review.

The panel reviewed each selected death to determine, among other things, whether or not it could have been prevented. Table 4 reports the percent of reviewed deaths in each Area deemed preventable. When SIDS is excluded, almost half of

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the selected deaths in Aberdeen, Billings and Portland are deemed maybe or definitely preventable. Referencing Figure 1, preventable deaths include those resulting from injuries, infectious diseases, and many of the death certificate ill-defined causes.

The Panel also looked at the factors contributing to deaths, and for each case determined which ones were relevant. Table 5 shows the percent of non-SIDS deaths for which each factor was rated as Highly or Moderately important to infant death. Family factors were deemed relevant to death in over half of the non-SIDS deaths reviewed, with System of Care and Provider factors rated as important in less than one quarter of the reviewed deaths. Community factors were deemed relevant in about 25% of the non-SIDS deaths.

The second column in Table 5 reports the percent of deaths for which the factors were deemed preventable, that is, where effective interventions could modify their impact on infant death. The Panel felt that in almost half of the deaths, family factors could be modified to decrease infant mortality, and in about a third of the other cases, interventions could prevent mortality. Interventions suggested included: health education, parenting education, substance abuse programs, and mental health counseling. System of care factors that the Panel believed could be
modified included: transportation issues, consultation and referral policies and availability of health care providers in remote areas.

For each case reviewed, the panel chose one of the four factors as most important in explaining the infant's death. Table 6 depicts the percentage of SIDS and non-SIDS deaths falling into each factor category. For non-SIDS deaths family factors were deemed as most important in over 15% of the cases, and rated higher than any of the other factors except the cause of death itself. All SIDS deaths were deemed attributable to the cause of death only.

Unfortunately, much of the factor information available for many deaths the panel reviewed was inadequate. According to Table 7, for almost half of the non-SIDS deaths there was no or low certainty about community and provider factors and their contribution to many infant deaths. Although, there appeared to be more family and system of care information, in a third of the cases, the panel still rated the certainty of the information as low.

For SIDS deaths, it appears that hardly any family, community, system of care or provider information is collected and recorded after diagnoses are made. Curtailing
the investigative process in this way hampers infant mortality review and exact cause of death determination.

IV. Recommendations

Based on the findings reported in this summary, the following recommendations are offered to the Indian Health Service for further research on infant mortality to provide guidance in lowering rates.

I. Better determination of the cause of death.

In order to design effective interventions for lowering infant mortality, it is necessary to determine first exactly why infants die. We have found cause of death determination on death certificates to be accurate for SIDS deaths, but less accurate for other types of deaths. Procedures can be developed for determining cause of death and policies instituted to ensure that the process is carried out uniformly across IHS Areas.

II. Performance of Comprehensive Infant Mortality Review for all Infant Deaths.

Service unit staff should perform reviews of all infant deaths as soon as possible. The review team should include medical personnel involved in the case as well community health workers who are familiar with the family and community environments. Reviews should be
conducted using a systematic format so that all aspects of a deceased infant's care are considered. The Project has found that family, community, system of care and provider factors are all important when analyzing infant deaths, and these should be considered in the development of a format for infant mortality review.

It would helpful if the IHS were to develop a procedure for reviewing infant deaths and charge one individual in each Area with implementing the reviews according to the procedure at the Service Unit level. Time frames for the performance of reviews as well as checklists of items to be covered would assist Service Unit staff in performing reviews.

III. Improved Data Collection on all Infant Deaths.

A form for gathering data on infant deaths should be developed by Headquarters staff with input from maternal and child health staff in the twelve Areas. It would be helpful to consider other infant mortality review efforts in the development of the data collection tool so that the resulting data base would provide data comparable to that available for other races. The form should include information from birth and death certificates and medical records. In
addition, data should be collected on community and family factors. The form should be easy to complete and contain fields for easy computerization.

After the review of each infant death, Service Unit staff should complete the form and submit it to IHS Headquarters, where an infant mortality data base should be maintained. Strict rules regarding submission and verification of data should be developed to ensure that the data base accurately reflects infant mortality in the twelve Areas. In addition, confidentiality for families, community people and medical personnel must be maintained.

IV. Aggregation and Reporting of Data.

It should be the responsibility of the IHS Headquarters staff to maintain the infant mortality data base, aggregate the data in meaningful ways and produce reports for use by field and headquarters staff. Areas should regularly receive reports on their infant deaths and how their profile of deaths compares to other Areas. Headquarters staff should work with Area staff on an ongoing basis to ensure proper and complete submission of data. An annual IHS infant mortality report should be produced.
V. Further Study of SIDS Among Native Americans.
In order to show measurable progress in lowering death rates for Indian infants in the Aberdeen, Alaska, Billings and Portland Areas, SIDS must be studied in a rigorous and comprehensive research design. We envision one that goes far beyond what this Project was capable of, both in terms of time and scope.

We have attempted to distinguish real SIDS from other unexplained or inaccurately diagnosed deaths by having each infant death reviewed by an expert panel and a cause of death assigned. Postneonatal deaths from four IHS areas for three years were reviewed resulting in data on 305 infant deaths. One hundred and sixty-six of these were coded as SIDS on death certificates, with fifteen subsequently changed by the panel to "possible SIDS" and another twelve to other causes of death. In addition, thirteen that were not coded as SIDS on the death certificate were determined by the panel to be cases of SIDS or "possible SIDS". The result is that the project's expert panel looked at 149 SIDS deaths in depth for the four sites over three years.

According to the IHS, the rate of SIDS varies from 6.2/1000 live births in the Aberdeen Area to a low of 5.3/1000 live births in the Alaska Area. Billings and
Portland Areas fall in the middle with respective rates of 5.8 and 6.2 per thousand live births. SIDS rates for other IHS Areas, Navajo in particular (1.0/1000 live births), are significantly lower, as are rates for other races. The national SIDS average for all races is 1.3/1000 live births. In the four project areas, the SIDS rates for whites is less than half the Indian rate. In addition, about half of the infant deaths for the project areas are attributable to SIDS, and this situ of only about a third of the infant deaths for all races.

Since SIDS is the most substantial contributor to Indian infant deaths, we believe that gains in infant mortality for this population will come about only when systematic and valid studies of its causes are completed. Figure 4 depicts the potential for reducing Indian infant mortality by eliminating preventable deaths as well as those attributed to SIDS.

We recommend that the IHS convene a work group to outline a major research initiative in this area. Membership on the work group should include: maternal and child health staff from the IHS and other government agencies and representatives from the National SIDS Foundation, the American Academy of
Pediatrics and the SIDS research community. We expect that twenty individuals would comprise the ideal size for this work group, and that a two day meeting would be sufficient for initial idea generation. After the initial meeting, a smaller group can work to refine the search plan.
Table 1

Native Infant Deaths By Area

Number (rate per 1,000 live births)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aberdeen</td>
<td>28 (8.8)</td>
<td>41 (12.9)</td>
<td>19 (5.5)</td>
<td>33 (10.5)</td>
<td>15 (5.6)</td>
<td>27 (8.9)</td>
</tr>
<tr>
<td>Alaska</td>
<td>19 (7.0)</td>
<td>19 (7.0)</td>
<td>22 (6.0)</td>
<td>23 (8.8)</td>
<td>17 (4.5)</td>
<td>25 (10.1)</td>
</tr>
<tr>
<td>Billings</td>
<td>13 (7.4)</td>
<td>19 (10.8)</td>
<td>10 (6.5)</td>
<td>14 (9.8)</td>
<td>3 (2.9)</td>
<td>11 (6.4)</td>
</tr>
<tr>
<td>Portland</td>
<td>17 (6.3)</td>
<td>19 (7.0)</td>
<td>11 (4.6)</td>
<td>20 (9.8)</td>
<td>17 (7.9)</td>
<td>21 (9.4)</td>
</tr>
<tr>
<td>Total</td>
<td>77 (7.4)</td>
<td>98 (9.5)</td>
<td>62 (5.6)</td>
<td>90 (9.8)</td>
<td>52 (5.6)</td>
<td>84 (9.0)</td>
</tr>
</tbody>
</table>

Ratio:
Postneonatal to Neonatal

1.3
1.4
1.6
Table 2

Causes of Death for non-SIDS
Deaths Reviewed by Panel

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infectious Disease</td>
<td>17</td>
<td>10.9</td>
</tr>
<tr>
<td>Nutritional</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>CNS, Sense Organ Dis</td>
<td>7</td>
<td>4.5</td>
</tr>
<tr>
<td>Circulatory Disease</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Respiratory Disease</td>
<td>16</td>
<td>10.3</td>
</tr>
<tr>
<td>GI Disease</td>
<td>1</td>
<td>.6</td>
</tr>
<tr>
<td>Congenital Anomalies</td>
<td>18</td>
<td>11.5</td>
</tr>
<tr>
<td>Perinatal Conditions</td>
<td>17</td>
<td>10.9</td>
</tr>
<tr>
<td>Unknown/ Ill Defined</td>
<td>12</td>
<td>7.7</td>
</tr>
<tr>
<td>Unknown/Possible SIDS</td>
<td>42</td>
<td>26.9</td>
</tr>
<tr>
<td>Accidents</td>
<td>5</td>
<td>3.2</td>
</tr>
<tr>
<td>Injury/Poisoning</td>
<td>9</td>
<td>5.8</td>
</tr>
<tr>
<td>Child Abuse/Homicide</td>
<td>5</td>
<td>3.2</td>
</tr>
<tr>
<td>Complicat Med/Surg.</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>156</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Table 3

Percent of SIDS and nonSIDS Deaths with High Accuracy as to the Cause of Death on the Death Certificate

<table>
<thead>
<tr>
<th>Area</th>
<th>SIDS (n)</th>
<th>NON-SIDS (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>77.5 (40)</td>
<td>49.3 (67)</td>
</tr>
<tr>
<td>Aberdeen</td>
<td>86.8 (38)</td>
<td>62.9 (35)</td>
</tr>
<tr>
<td>Billings</td>
<td>100 (23)</td>
<td>48.0 (25)</td>
</tr>
<tr>
<td>Portland</td>
<td>97.9 (48)</td>
<td>67.9 (28)</td>
</tr>
</tbody>
</table>
Table 4  
Percent of nonSIDS Deaths Deemed Definitely or Maybe Preventable by Area  
(N = 156)  

<table>
<thead>
<tr>
<th>Area</th>
<th>%</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aberdeen</td>
<td>49.2</td>
<td>67</td>
</tr>
<tr>
<td>Alaska</td>
<td>37.1</td>
<td>35</td>
</tr>
<tr>
<td>Billings</td>
<td>40.0</td>
<td>25</td>
</tr>
<tr>
<td>Portland</td>
<td>41.3</td>
<td>29</td>
</tr>
</tbody>
</table>
Table 5

Percent of nonSIDS Deaths with Factors Rated as Highly or Moderately Relevant to Death and as Maybe or Definitely Preventable

Total N = 118

<table>
<thead>
<tr>
<th>Factor</th>
<th>Highly or Moderately Relevant to Death</th>
<th>Maybe or Definitely Preventable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>52</td>
<td>49.1</td>
</tr>
<tr>
<td>Community</td>
<td>26.3</td>
<td>31.4</td>
</tr>
<tr>
<td>System of Care</td>
<td>20.3</td>
<td>37.3</td>
</tr>
<tr>
<td>Provider</td>
<td>17.8</td>
<td>34.7</td>
</tr>
</tbody>
</table>
Table 6

Most Important Factor for Death for SIDS and nonSIDS Deaths

(Percent of deaths)

<table>
<thead>
<tr>
<th>Factor</th>
<th>SIDS</th>
<th>NON-SIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>0</td>
<td>15.4</td>
</tr>
<tr>
<td>Community</td>
<td>0</td>
<td>.6</td>
</tr>
<tr>
<td>System of Care</td>
<td>0</td>
<td>.6</td>
</tr>
<tr>
<td>Provider</td>
<td>0</td>
<td>4.5</td>
</tr>
<tr>
<td>Cause of Death</td>
<td>100</td>
<td>78.2</td>
</tr>
<tr>
<td>TOTAL N</td>
<td>149</td>
<td>156</td>
</tr>
</tbody>
</table>
Table 7

Percent of SIDS and non SIDS Deaths With No or Low Certainty of Information for Factors Contributing to Death

<table>
<thead>
<tr>
<th>FACTOR</th>
<th>SIDS</th>
<th>NON-SIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>90.6</td>
<td>35.3</td>
</tr>
<tr>
<td>Community</td>
<td>93.3</td>
<td>42.4</td>
</tr>
<tr>
<td>System of Care</td>
<td>87.3</td>
<td>34.8</td>
</tr>
<tr>
<td>Provider</td>
<td>85.9</td>
<td>43.2</td>
</tr>
</tbody>
</table>
Abstract

Purpose:
This study was conducted to verify the rates, causality, and associated risk factors for American Indian and Alaska Native (AI/AN) infant deaths in 10 states.

Methods:
A retrospective descriptive study was carried out for the 3-year period 1986-1988 by matching copies of death and birth certificates, expanding the data base with medical and social information about the infants and their families, and analyzing contributing factors through a panel of pediatric specialists. Families were not interviewed.

Results:
Comparison of the cohort of deceased infants in the 10 states with national Indian and all races infants dying in the same period revealed several important factors. Sudden infant death syndrome was 4 times higher than the U.S. all races rate and 3 times higher than the national rate for all Indians. Deaths from combined effects of prematurity were 4 times greater than the national Indian rate, the latter being comparable to the U.S. white rate. Infant deaths due to congenital anomalies were not significantly higher than the U.S. Indian rate or than the U.S. all races rate.

Conclusion:
Regional differences in the health of AI/AN infants exist. Infant deaths appear to be associated with high maternal behavioral risk factors. Monitoring of infant health must be a collaborative effort between IHS and the states. Special attention should be given to family planning and birth spacing.
American Academy of Pediatrics
Native American Postneonatal Mortality Project
Indian Health Service
Final Report
Grant #240-87-0055 PHS

September 30, 1991
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Tallies of the number of neonatal and postneonatal deaths for each study Area for each year are reported in Table 1. Neonatal deaths are those that occurred in the first 28 days of life, and postneonatal deaths are those that occurred in days 29 through 364. A total of 463 native infant deaths were recorded for the four Areas. In each Area, and for each of the years 1986 to 1988, the rate of postneonatal death exceeds the neonatal death rate. When compared to the number of neonatal deaths, postneonatal deaths vary from almost equal to twice as frequent over the three year
III. Panel Process

The project convened a scientific advisory panel in each of the IHS Areas to perform indepth infant mortality reviews. Unlike traditional medical audits, which rely mainly on clinical information found in medical records, infant mortality review generally includes consideration of not only medical but socioeconomic, public health, behavioral, educational and health systems factors which may have contributed to the deaths of infants. Because infant death review searches more widely than traditional medical audits for factors which may be implicated in infant deaths, it was necessary that our team of reviewers begin the process of infant death review with an underlying framework which defined both the domains to be considered in the review process and the content encompassed within each domain. Our review team included members of different disciplines, including public health nursing, pathology, pediatrics, public health and SIDS. It was important that team members explicitly acknowledged that the review encompasses factors broader than any one individual's area of expertise, agreed on what these factors included, and abided by these domains during the review process. The process of agreeing on an underlying conceptual framework ensured that everyone around the table agreed on the meaning of various terms and attempted to apply them uniformly.
parity, recent family death, marital disputes, family illness, grandmother intercedence).

Unavailability of services, inaccessibility of services, distance to a full-service clinic, the adequacy of community health nursing coverage, as well as the mix, training, and coverage provided by IHS Service Unit personnel were among relevant health care system factors which may contribute to infant deaths. Also important are Service Unit policies which may contribute to delayed or inadequate care. These would include aspects of clinic management, accessibility of family planning, the characteristics of the referral network, aspects of pharmacy policy, as well as the degree of tribal or community input into Service Unit policies. Finally, health care system factors also included such matters as the accessibility of Medicaid eligibility to the Native American population and the health care resources available to Native Americans not residing in IHS direct or contract service areas and to those not eligible for the assistance of the Indian Health Service.

Medical care provides factors included evidence of delay in diagnosis, treatment, or follow-up; misdiagnosis; evidence of failure to refer or seek consultation; lack of treatment plans and assurance of case management; and evidence of poor communication between providers (including transmission of
the accuracy score coded in item 4 would also be rated as low.

In addition to evaluating the accuracy of the cause of death as a recorded on the death certificate, the panel felt it was important to make some judgment about the degree to which the cause of death was preventable and the degree of their certainty about this judgment. This information was recorded in line 6. The preventability of some causes of death were judged to be unknown. Alternatively, they were judged as either having been unpreventable, possibly preventable, or preventable. In addition, panelists were given the opportunity to indicate that they had no information upon which to make this judgment. Alternatively, if information was available, they had the opportunity to indicate a low, moderate, or high degree of certainty in making this judgment.

Most of the remaining information collected on the infant death review form summarized the panel's evaluation of the role of various factors in each infant death. Separate evaluation was made of each of the four factors named earlier: family factors, community/cultural factors, system of care factors, and provision of care factors. For each factor, a determination was first made of its overall relevance to the death; the factor was judged as either not
In recognition of the fact that Native American infants obtain health care under several different service systems, the infant death review form notes the major source of the infant's care as either having been from the Indian Health Service, from a provider under contract with the IHS, or from a non-IHS facility or provider.

The panel reviewed each infant death individually, beginning its work with a thorough review of a summary developed on each case. Following review and discussion of the case summary, the infant death review tool was completed not by individual team members, but by the team as a whole. At times, extensive discussion was necessary in order to reach agreement among team members about the coding of individual items.

Not all infant deaths were reviewed. The Project Advisory Committee delineated the following criteria for selection of deaths for review by the Panel:

1) All SIDS deaths;
2) All cases with unknown causes of death;
3) All cases with questionable causes of death;
4) No cases in which infants never left the hospital;

This yielded 305 infant deaths for Panel review over the three years of the Project. One hundred and forty-nine of these were SIDS (48%) with the remaining causes of death
the selected deaths in Aberdeen, Billings and Portland are deemed maybe or definitely preventable. Referencing Figure 1, preventable deaths include those resulting from injuries, infectious diseases, and many of the death certificate ill-defined causes.

The Panel also looked at the factors contributing to deaths, and for each case determined which ones were relevant. Table 5 shows the percent of non-SIDS deaths for which each factor was rated as Highly or Moderately important to infant death. Family factors were deemed relevant to death in over half of the non-SIDS deaths reviewed, with System of Care and Provider factors rated as important in less than one quarter of the reviewed deaths. Community factors were deemed relevant in about 25% of the non-SIDS deaths.

The second column in Table 5 reports the percent of deaths for which the factors were deemed preventable, that is, where effective interventions could modify their impact on infant death. The Panel felt that in almost half of the deaths, family factors could be modified to decrease infant mortality, and in about a third of the other cases, interventions could prevent mortality. Interventions suggested included: health education, parenting education, substance abuse programs, and mental health counseling. System of care factors that the Panel believed could be
the investigative process in this way hampers infant mortality review and exact cause of death determination.

IV. Recommendations

Based on the findings reported in this summary, the following recommendations are offered to the Indian Health Service for further research on infant mortality to provide guidance in lowering rates.

I. Better determination of the cause of death.

In order to design effective interventions for lowering infant mortality, it is necessary to determine first exactly why infants die. We have found cause of death determination on death certificates to be accurate for SIDS deaths, but less accurate for other types of deaths. Procedures can be developed for determining cause of death and policies instituted to ensure that the process is carried out uniformly across IHS Areas.

II. Performance of Comprehensive Infant Mortality Review for all Infant Deaths.

Service unit staff should perform reviews of all infant deaths as soon as possible. The review team should include medical personnel involved in the case as well community health workers who are familiar with the family and community environments. Reviews should be
addition, data should be collected on community and family factors. The form should be easy to complete and contain fields for easy computerization.

After the review of each infant death, Service Unit staff should complete the form and submit it to IHS Headquarters, where an infant mortality data base should be maintained. Strict rules regarding submission and verification of data should be developed to ensure that the data base accurately reflects infant mortality in the twelve Areas. In addition, confidentiality for families, community people and medical personnel must be maintained.

IV. Aggregation and Reporting of Data.

It should be the responsibility of the IHS Headquarters staff to maintain the infant mortality data base, aggregate the data in meaningful ways and produce reports for use by field and headquarters staff. Areas should regularly receive reports on their infant deaths and how their profile of deaths compares to other Areas. Headquarters staff should work with Area staff on an ongoing basis to ensure proper and complete submission of data. An annual IHS infant mortality report should be produced.
Portland Areas fall in the middle with respective rates of 5.8 and 6.2 per thousand live births. SIDS rates for other IHS Areas, Navajo in particular (1.0/1000 live births), are significantly lower, as are rates for other races. The national SIDS average for all races is 1.3/1000 live births. In the four project areas, the SIDS rates for whites is less than half the Indian rate. In addition, about half of the infant deaths for the project areas are attributable to SIDS, and this result of only about a third of the infant deaths for all races.

Since SIDS is the most substantial contributor to Indian infant deaths, we believe that gains in infant mortality for this population will come about only when systematic and valid studies of its causes are completed. Figure 4 depicts the potential for reducing Indian infant mortality by eliminating preventable deaths as well as those attributed to SIDS.

We recommend that the IHS convene a work group to outline a major research initiative in this area. Membership on the work group should include: maternal and child health staff from the IHS and other government agencies and representatives from the National SIDS Foundation, the American Academy of
Table 1
Native Infant Deaths By Area
Number (rate per 1,000 live births)

<table>
<thead>
<tr>
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<td>28</td>
<td>41</td>
<td>19</td>
<td>33</td>
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<td>27</td>
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<tr>
<td></td>
<td>(8.8)</td>
<td>(12.9)</td>
<td>(5.5)</td>
<td>(10.5)</td>
<td>(5.6)</td>
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<td>19</td>
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<td>23</td>
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<td>(7.0)</td>
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<td>(6.0)</td>
<td>(8.8)</td>
<td>(4.5)</td>
<td>(10.1)</td>
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<tr>
<td>Billings</td>
<td>13</td>
<td>19</td>
<td>10</td>
<td>14</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>(7.4)</td>
<td>(10.8)</td>
<td>(6.5)</td>
<td>(9.8)</td>
<td>(2.9)</td>
<td>(6.4)</td>
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<tr>
<td>Portland</td>
<td>17</td>
<td>19</td>
<td>11</td>
<td>20</td>
<td>17</td>
<td>21</td>
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<tr>
<td></td>
<td>(6.3)</td>
<td>(7.0)</td>
<td>(4.6)</td>
<td>(9.8)</td>
<td>(7.9)</td>
<td>(9.4)</td>
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<td>Total</td>
<td>77</td>
<td>98</td>
<td>62</td>
<td>90</td>
<td>52</td>
<td>84</td>
</tr>
<tr>
<td></td>
<td>(7.4)</td>
<td>(9.5)</td>
<td>(5.6)</td>
<td>(9.8)</td>
<td>(5.6)</td>
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Ratio:
Postneonatal to Neonatal

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<tr>
<td>Ratio</td>
<td>1.3</td>
<td>1.4</td>
<td>1.6</td>
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Table 3

Percent of SIDS and nonSIDS Deaths with High Accuracy as to the Cause of Death on the Death Certificate

<table>
<thead>
<tr>
<th>Area</th>
<th>SIDS</th>
<th>(n)</th>
<th>NON-SIDS</th>
<th>(n)</th>
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</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>77.5</td>
<td>(40)</td>
<td>49.3</td>
<td>(67)</td>
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<td>Aberdeen</td>
<td>86.8</td>
<td>(38)</td>
<td>62.9</td>
<td>(35)</td>
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<tr>
<td>Billings</td>
<td>100</td>
<td>(23)</td>
<td>48.0</td>
<td>(25)</td>
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<tr>
<td>Portland</td>
<td>97.9</td>
<td>(48)</td>
<td>67.9</td>
<td>(28)</td>
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</tbody>
</table>
Table 5

Percent of nonSIDS Deaths with Factors Rated as Highly or Moderately Relevant to Death and as Maybe or Definitely Preventable

Total N = 118

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<thead>
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<th>Factor</th>
<th>Highly or Moderately Relevant to Death</th>
<th>Maybe or Definitely Preventable</th>
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<td>Family</td>
<td>52</td>
<td>49.1</td>
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<tr>
<td>Community</td>
<td>26.3</td>
<td>31.4</td>
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<tr>
<td>System of Care</td>
<td>20.3</td>
<td>37.3</td>
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<tr>
<td>Provider</td>
<td>17.8</td>
<td>34.7</td>
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<td>FACTOR</td>
<td>SIDS</td>
<td>NON-SIDS</td>
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<tr>
<td>-------------------</td>
<td>-------</td>
<td>----------</td>
</tr>
<tr>
<td>Family</td>
<td>90.6</td>
<td>35.3</td>
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<tr>
<td>Community</td>
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<td>System of Care</td>
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<tr>
<td>Provider</td>
<td>85.9</td>
<td>43.2</td>
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American Indian, Alaska Native
AAP Post-Neonatal Mortality Study
Grouped Cause of Death 1986-1988

- SIDS 49%
- Unknown 18%
- Perinatal 6%
- Congenital Anomalies 6%
- Respiratory 5%
- CNS/Sense Organs 2%
- Infectious Disease 6%
- Accid/Injury/Poison 5%
- All Other 3%
- Child Abuse 2%

Alaska Aberdeen Billings Portland Areas
Potential Reduction in Post-Neonatal Mortality Rates
American Indians and Alaska Natives – IHS Service Area
Alaska, Aberdeen, Billings, Portland Areas
1986-1988

Births 29278 (IHS Births)
Neonatal Deaths 200 (Study Deaths)
Post-Neonatal Deaths 305 (Study Deaths)
Total Deaths 505 (Study Deaths)

Rates:
Infant Mortality 17.2
Neonatal Mortality 6.8
Post-Neonatal Mortality 10.4

Total Deaths 505
- Neonatal 200 (39.6%)
- Post-Neonatal 305 (60.4%)

Eliminate SIDS
Infant Mortality 13.7
Post-Neonatal 6.9

Eliminate Possibly Preventable Deaths
Infant Mortality 15.4
Post-Neonatal 8.6

Eliminate SIDS & Possibly Preventable Deaths
Infant Mortality 11.9
Post-Neonatal 5.0

DRAFT
David W. Kaplan M.D. 2/1/91 *** Do not Cite, Quote, or Duplicate ***