# *Healthy Native Babies*

## Project Workbook and Toolkit

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National Institutes of Health

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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# *Healthy Native Babies Project*

## Workbook and Toolkit

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*Healthy Native Babies Project* Workgroup

Developed with the
Native American Management Services
under contract 3HHSN275200503412C

June 2010

The information and materials created for the *Healthy Native Babies Project* were crafted with care and revised with the feedback of American Indian/Alaska Native (AI/AN) community members, who used the messages at numerous trainings held in U.S. Northern Tier communities.

Just as  one size fits all  does not really apply to clothing, it does not apply to every AI/AN community that will use the *Healthy Native Babies Project* materials. While it is important to be consistent about the basic overall safe sleep messages, we encourage you to highlight those that best address and tailor those to best address the issues of greatest concern for your community. It is our sincere hope that your success will lead to a reduction in the disparate number of AI/AN babies dying of Sudden Unexpected Infant Death (SUID)/Sudden Infant Death Syndrome (SIDS).

***Healthy Native Babies Project* Workgroup**

In memory of Carole Anne Heart

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## Chapter 1:

# Facts About Sudden Infant Death Syndrome (SIDS)

### Objectives

By the end of this chapter the learner will be able to:

- Define SIDS.
- Explain how many infants die of SIDS and recognize the disproportionately higher SIDS rates among American Indian/Alaska Native (AI/AN) infants.
- Describe what is currently known about SIDS causes and risk factors, especially risk factors common in AI/AN communities.

## What is SIDS?

SIDS is the term used to describe the unexpected death of an infant younger than one year of age that remains unexplained after a thorough investigation.

Each year in the United States, more than 4,500 infants die suddenly from no obvious cause. These deaths, called Sudden Unexpected Infant Death (SUID), occur suddenly and unexpectedly and the cause of death is not immediately obvious before an investigation. The SUID category includes both explained infant deaths, such as poisoning or car accident, and unexplained infant deaths. SIDS is listed as the cause of one-half of all deaths in the SUID category. SIDS is also the leading cause of all deaths among infants between one month and one year of age.

Visit **Appendix 1** for a list of abbreviations and acronyms and their explanations.

A diagnosis of SIDS is made by collecting information, conducting scientific or forensic tests, and talking with parents, other caregivers, and health care providers. If, after this process is complete, there is still no identifiable cause of death, the infant's death might be labeled as SIDS.

SIDS is defined as:
*The sudden death of an infant younger than one year of age that remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.*[1]

The exact cause or causes of SIDS are not known. Based on scientific research, researchers now believe that babies who die of SIDS may be born especially vulnerable to both internal influences, such as brain abnormalities, and external influences, such as exposure to tobacco smoke in the environment.

Even though there is no certain way to prevent SIDS or to predict which infants may die of SIDS, there are ways to reduce an infant's risk for SIDS; these risk-reduction strategies are explained in the Chapter 2 of this Workbook.

## How many infants die of SIDS?

The most current data from the Centers for Disease Control and Prevention (CDC) show that 2,323 infants died of SIDS in the United States in 2006. Although the overall SIDS rate in the United States has been steadily declining since the early 1990s, SIDS

[1]Willinger, M., James, L.S., & Catz, C. (1991). Defining sudden infant death syndrome (SIDS): Deliberation of an expert panel convened by the National Institute of Child Health and Human Development (NICHD). *Pediatric Pathology*, *11*(5), 677-684.

rates remain high among certain groups, including American Indians/Alaska Natives (AI/ANs). Efforts to further reduce SIDS need to continue, especially within groups at higher risk.

## An Important Decline

Between 1983 and 1992, the average number of SIDS deaths reported in the United States ranged from 5,000 to 6,000 each year. In 1992, the American Academy of Pediatrics (AAP) Task Force on Infant Sleep Position and SIDS (now called the AAP Task Force on SIDS, and called the AAP Task Force in this Workbook) recommended that all healthy babies younger than one year of age be placed to sleep on their backs or sides to reduce the risk of SIDS. This recommendation came after many international research studies reported that infants who slept on their stomachs had a significantly higher risk of dying from SIDS than those who slept on their sides or backs.

In 1994, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and a number of partners, including the AAP, the Maternal and Child Health Bureau of the Health Resources and Services Administration, the SIDS Alliance (now called First Candle/SIDS Alliance), and the Association of SIDS and Infant Mortality Programs, launched the *Back to Sleep* campaign to raise awareness among parents and caregivers about ways to reduce the risk of SIDS. The campaign's top recommendation for reducing the risk of SIDS was to place healthy infants on their backs to sleep.

In 1996, after more data were gathered about the dangers posed to infants who slept on their stomachs, the AAP Task Force recommended that all healthy babies be placed to sleep *wholly on their backs*, the position associated with the lowest SIDS risk. The AAP Task Force concluded that:

- Stomach sleeping poses the highest risk of SIDS;
- Side-lying position falls in between stomach and back sleeping in terms of risk; and
- "Back is best" for reducing a baby's risk of SIDS.

## SIDS is:

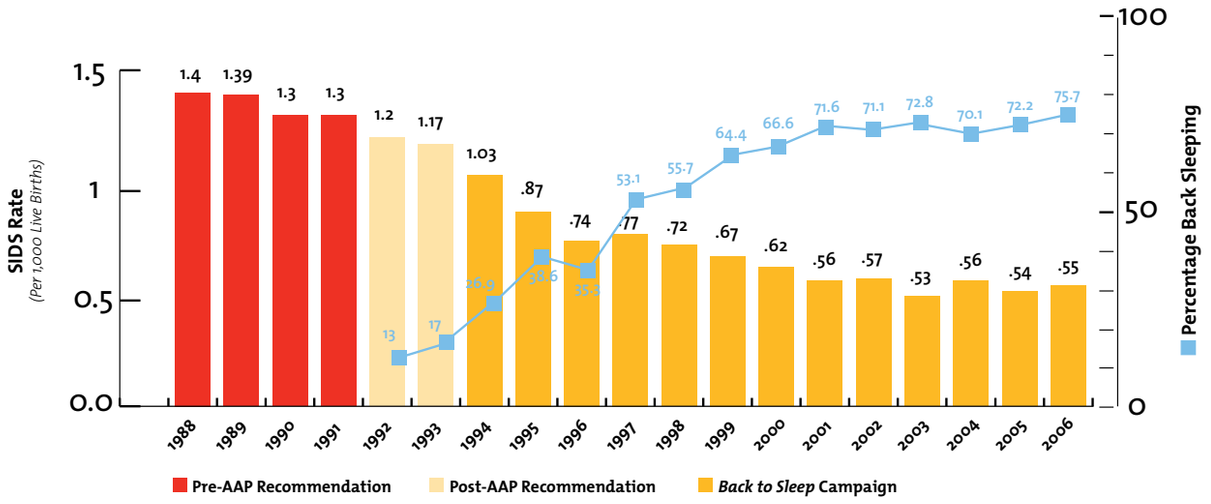
- The leading cause of death for infants between one month and one year of age, with most deaths occurring between two months and four months of age (90 percent of SIDS deaths occur by six months of age
- Least common during an infant s first postnatal month, between one day and 28 days after birth
- A sudden and silent medical disorder that can happen to an infant who seems to be healthy
- A death often associated with the sleep period and with little or no signs of suffering
- Determined only after an autopsy, examination of the death scene, and a review of the infant s and family s clinical histories
- A "diagnosis of exclusion," meaning the cause of death is labeled as SIDS only after ruling out other causes
- Slightly more common among male infants and slightly more common during the winter months
- A death which leaves unanswered questions and causes intense grief for parents, families, and communities

## SIDS is *not*:

- Entirely preventable, but the risk can be reduced
- The same as suffocation
- Caused by vomiting and/or choking
- Caused by diphtheria, pertussis, and tetanus (DPT) vaccine, or by other immunizations, shots, or vaccinations
- Contagious or catchable
- The result of child abuse or neglect
- Caused directly by cribs
- The cause of every unexpected infant death

*Figure 1.*

## U.S. SIDS Rate and Sleep Position, 1988 2006




*Sources:* SIDS rate source: National Center for Health Statistics, Centers for Disease Control and Prevention, Department of Health and Human Services.[27, 29] Sleep position data: *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Infant Sleep Position Study.[30, 31]

Data from 2004 indicate that the overall U.S. SIDS rate has declined by more than 50 percent since the AAP Task Force's initial recommendation in 1992. The SIDS rate among AI/ANs has also declined by about 50 percent since the 1990s. In addition, stomach and side sleeping decreased during the same period (see *Figure 1*). Many researchers, policy makers, and health care providers agree that declines in SIDS and stomach sleeping rates were assisted by public awareness campaigns, such as *Back to Sleep*.

### Is the decline in SIDS deaths real?

It is true that overall SIDS rates in the United States have declined, and that knowledge about SIDS has increased. But recent studies suggest that some deaths reported as SIDS would now be classified as "accidental suffocation or smothering" or from an "unknown or unspecified" cause. These data could mean that changes in reporting a cause of death may also play a slight role in the decrease reported since 1999.

Differences in autopsy procedures, death-scene examination, review of family/medical history, and other information could lead to inaccurate diagnosis. These differences could impact the reliability of some SIDS statistics and have implications for the family. It is important, then, that all those involved with gathering and reporting such data follow standard procedures to ensure consistent and reliable collection of information.

### More Work to Do

Despite the overall decline in U.S. SIDS rates, SIDS remains the leading cause of death among U.S. infants between one month and one year of age. SIDS is also the third leading cause of death overall among U.S. infants younger than one year of age. Even more troubling is the fact that SIDS rates remain high among certain ethnic/racial groups in the United States, including AI/ANs.

The SIDS rate for AI/ANs is two to four times higher than the national average (see *Figure 2*). SIDS is the leading single cause of post-neonatal deaths (deaths that occur between 28 days and one year of age) for AI/AN infants.

A further breakdown of the data shows some important trends in the SIDS rates for AI/ANs in Indian Health Service (IHS) Areas compared to

urban Indians. (The *Healthy Native Babies Project* focuses on five IHS areas.) *Figure 3* shows the SIDS rates for those who reside in these IHS areas compared to the overall rate for all IHS areas and compared to the SIDS rate for all races, for the period 2002 to 2004. *Figure 4* compares the SIDS rate for urban Indians in large metropolitan counties across the United States to the SIDS rate for all races in the same counties for the period 1997 to 2003.

*Figure 2.*

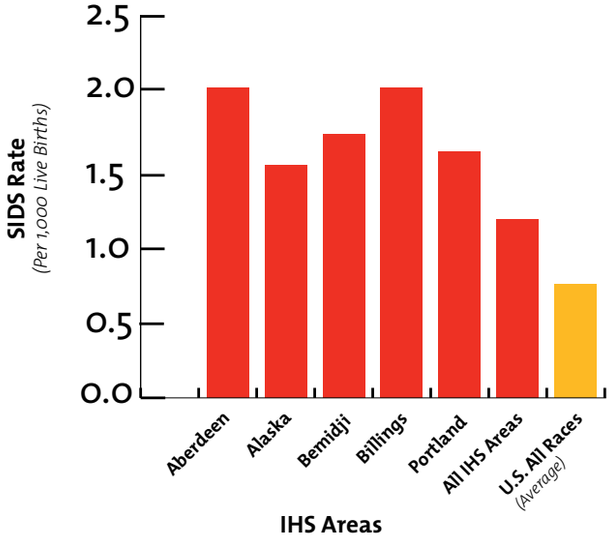
## SIDS Deaths by Race/Ethnic Origin of the Mother, 2005

| Race | Number | Rate Per 1,000 Live Births |
|---|---|---|
| All Races | 2,234 | 0.54 |
| **American Indian/Alaska Native** | **50** | **1.12** |
| African American | 580 | 0.99 |
| White | 1,264 | 0.55 |
| Hispanic | 277 | 0.28 |
| Asian/Pacific Islander | 55 | 0.24 |

*Source:* Matthews, T.J., Menacker, F., & MacDorman, M.F. (2008). Infant mortality statistics from the 2005 period linked birth/infant death data set. *National Vital Statistics Report*, 52(2).

*Figure 3.*

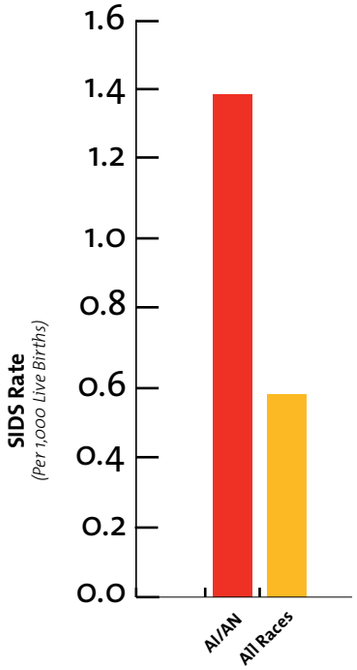
## AI/AN SIDS Rates for IHS Area Counties 2002 2004*




*Source:* National Center for Health Statistics, prepared by IHS Office of Program Statistics

*Figure 4.*

## AI/AN SIDS Rates for Urban Indian Health Organization Counties, 1997 2003*

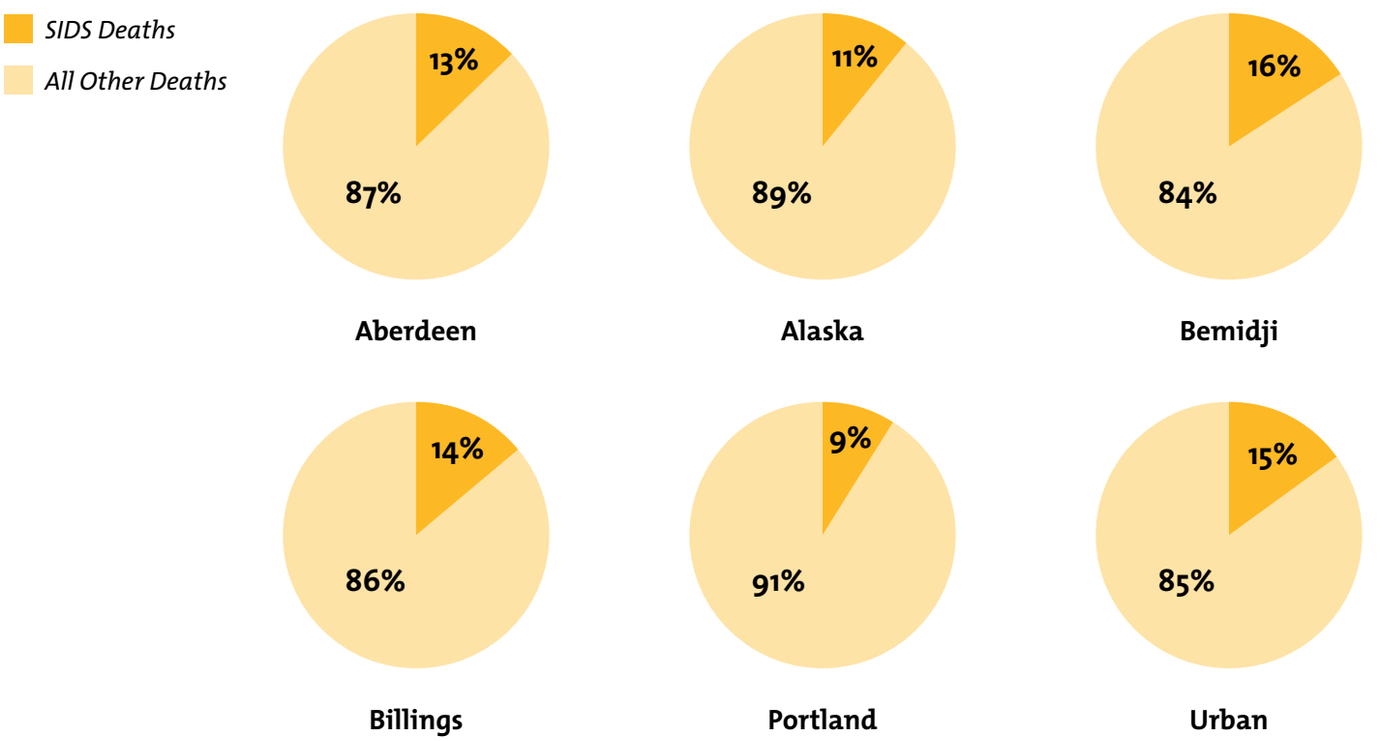


The pie charts in *Figure 5* compare the SIDS rate for each IHS Area with the rates of all other causes of death. It is important to note that each of the IHS Areas had a SIDS rate greater than the overall SIDS rate for AI/ANs and more than three times the SIDS rate for all races in the United States.

Just as the work of the *Back to Sleep* campaign has been critical to increasing awareness about SIDS and to decreasing SIDS rates and risk factors, your work within AI/AN communities is critical to addressing and eliminating disparities in SIDS rates. Outreach and education can make a difference in saving infant lives—and your efforts within these communities and IHS Areas are critical to making that difference.

*Figure 5.*

### SIDS Rates Versus All Other Causes of Death: IHS Areas




## What causes SIDS?

Researchers and health care providers don't know exactly what causes SIDS, but there are many theories.

### What is a neurotransmitter?

A neurotransmitter is a chemical that allows one nerve cell to send a nerve signal to another nerve cell(s).

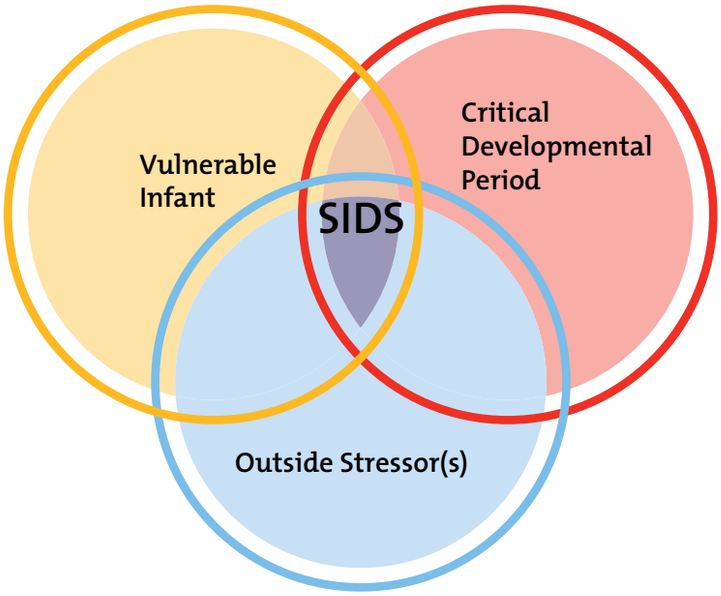
More and more research evidence suggests that some infants who die of SIDS are born with brain abnormalities or defects. These abnormalities are typically found within a network of nerve cells that rely on the neurotransmitter serotonin. The cells are located in part

of the brain stem that probably controls breathing, heart rate, blood pressure, temperature, and waking from sleep.

But scientists believe that brain defects alone may not be enough to cause a SIDS death. Evidence suggests that other events, such as not getting enough oxygen, getting too much carbon dioxide, overheating, or having an infection, must also occur for an infant to die from SIDS. Researchers use the *Triple-Risk Theory* to explain this concept. In this theory, all three factors have to be present for SIDS to occur. Having only one of these features may not be enough to cause death from SIDS, but when all three combine, the likelihood of SIDS is high (*Figure 6*). These factors are:

*Figure 6.*

## Triple-Risk Theory




Adapted from Filiano & Kinney 1994.

- **Vulnerable Infant.** The infant has an unknown body defect or brain abnormality, which puts him or her in a weak position. The unknown problem could be a defect in the part of the brain (called the arcuate nucleus) that controls breathing and waking from sleep; or it could be a mutation or change in the infant's genes that impacts how the body works. As a result, the infant might not be able to respond to different situations, such as when he or she isn't getting enough oxygen or when he or she is taking in too much carbon dioxide. The vulnerable infant might not be able to awaken from sleep the way a normal infant does. Health care providers, parents, and families don't know about these problems, so there is no way to know which infants are vulnerable.

- **Critical Developmental Period.** During the first six months after birth, infants go through many quick phases of growth that can change the body's ability to adjust or regulate itself—its temperature, breathing rate, heart rate, and sleeping and waking patterns. Some of these changes may make the infant's body systems unstable. It is hard for health care providers to know when an infant's internal system is unstable or how long it might be that way. It is impossible for parents and families to know when these critical periods are taking place.

- **Environmental Stress(es).** All infants encounter stresses in their environments. These situations (sometimes called external or outside stressors) can include being placed to sleep on the stomach, tobacco smoke in the environment, overheating, and infections. Infants who have no problems like those explained above can usually correct or overcome such external stresses to survive and thrive. But, an infant who is vulnerable and whose body system is unstable because of a critical developmental period might not be able to overcome these stresses.

According to the Triple-Risk Theory, all three situations must be present for SIDS to occur:

1. First, the baby has an unknown or undetected problem or vulnerability.
2. Then, as the infant goes through a critical developmental period, his or her body systems are unstable.
3. Finally, the infant encounters one or more environmental stresses, but, because of the first two situations, he or she can't overcome the stresses and dies from SIDS.

For example, many babies experience low oxygen levels and high carbon dioxide levels when they have respiratory infections. Or they might re-breathe air they've already breathed out, which is high in carbon dioxide and low in oxygen, when this air becomes trapped in bedding while they sleep on their stomachs. Normally, infants sense these situations, and their brains make them wake up or change their heartbeats or breathing to get more oxygen. If the infant is vulnerable because of a brain defect, these protective triggers might be missing, so the child may die of SIDS. Such a scenario might explain why babies who sleep on their stomachs are at higher risk for SIDS.

For resources and supporting information on SIDS and SIDS risk factors, see **Appendix 5**.

Removing one of these factors from the situation may tip the balance in favor of the baby's survival. Because the first two factors—vulnerable infant and critical developmental period—either can't be seen or are hard to pinpoint, **the most effective way to improve an infant's outcome is to remove or reduce environmental stresses**. In the Triple-Risk Theory, all three factors must be present for SIDS to occur. If caregivers remove one of the factors—such as getting rid of an outside stressor by placing an infant to sleep on his or her back—they can significantly reduce the risk of SIDS.

## What factors increase the risk for SIDS?

Currently, there is no known way to completely prevent SIDS, but there are ways to reduce the risk. Several factors present before the baby is born, at birth, and throughout the first year can impact SIDS risk. Many of these factors can be controlled or changed to reduce risk.

Controllable risk factors, including those that might be more common in Native communities, that put infants at higher risk for SIDS are:

- Overheating during sleep
- Maternal alcohol use (during pregnancy and after the birth of the infant)
- Commercial tobacco use (during pregnancy and in the baby's living environment)
- Bed sharing (especially when the adult has used alcohol or drugs or is tired)
- Stomach sleeping during naps and at night
- Soft sleeping surfaces and loose, fluffy bedding

Let's examine each of these risk factors in more detail.

## Overheating

Studies show that an overheated baby is more likely to sleep too deeply and have a hard time waking up. This situation may play a role in SIDS.

Babies should be warm during sleep, but not too warm. An overheated infant might sweat, have damp hair, and show flushed/red cheeks, heat rash, and/or rapid breathing. Overheating can result from the room temperature being too high, from the infant wearing too many layers of clothes or blankets, or from both situations.

Studies show that SIDS deaths seem to occur more often during the winter months, when caregivers are more likely to overdress babies to keep them warm. As awareness about SIDS risk has increased, the rates of SIDS in winter and summer have evened out a bit. In the Aberdeen Area Infant Mortality Study, conducted among AI/AN families, researchers found that a baby's SIDS risk was higher if he or she was wearing two or more layers of clothing. Other research showed that overheating might increase the risk of SIDS if the baby is already sick with a cold or infection, even though having a cold or infection by itself is not a risk factor for SIDS.

**Safe sleep recommendations suggest dressing baby in light sleep clothing, without a blanket, and keeping the room at a temperature that is comfortable for an adult.**

If parents and caregivers choose to use a blanket in the baby's sleeping space, you can advise them to use the blanket safely (sometimes called the "feet to foot" method) in the following way:

- Place the baby with feet at the end of the crib or sleep space.
- Tuck the ends of the blanket under the mattress or pad. The blanket should come no higher than baby's chest level to help ensure safety.
- Make sure to keep the blanket away from the baby's face.
- Use only light sleep clothing—a diaper, onesie, t-shirt, or sleeper—under the blanket so that the baby sleeps comfortably and stays warm, but not too warm.

## What about swaddling?

Swaddling is a common practice that many believe helps a young infant feel safer and more secure. If caregivers swaddle the baby, it is important to consider what else the baby is wearing and the temperature where the baby is sleeping. A swaddled baby probably does not need an additional blanket in his or her sleep space. After about two months of age, infants may be moving around more in their sleep and will not need the

For resources on overheating and SIDS, see **Appendix 5**.

## Maternal Alcohol Use

### *Drinking Alcohol During Pregnancy*

During pregnancy, a baby eats and drinks everything that the mother eats or drinks, and alcohol is no exception. Using alcohol during pregnancy is known to cause both physical and mental problems, including permanent brain damage and developmental delays. The effect of alcohol depends on the mother's and baby's genes and on the amount of alcohol consumed. Based on research data, there is no safe level of alcohol consumption during pregnancy—this means that even one drink could be harmful and can increase a baby's risk for lifelong problems.

One of the most serious problems caused by alcohol use during pregnancy is **Fetal Alcohol Syndrome (FAS)** a group of lifelong problems that can include:

- Preterm birth (which also increases the risk for SIDS by itself)
- Low birth weight (which also increases the risk for SIDS by itself)
- Physical deformities
- Hearing and vision problems
- Growth deficits
- Problems with motor skills
- Learning difficulties and language problems
- Hyperactivity
- Attention, memory, and judgement problems

Maternal drinking during pregnancy increases an infant's risk for SIDS once he or she is born. For instance, the Aberdeen Area Infant Mortality Study, which included participants from 10 Northern Plains Indian communities, found that:

- Binge drinking (five or more drinks at one time) during the mother's first three months of pregnancy increased the risk of SIDS to eight times that of infants whose mothers did not drink.

- Any alcohol use three months before a woman got pregnant and during the first three months of pregnancy increased the risk of SIDS to six times that of infants whose mothers did not drink during the same time periods.

**Women who are planning to become pregnant or who are pregnant should not drink any alcohol.**

### *Drinking Alcohol After the Baby Is Born*

Drinking alcohol and then breastfeeding gives the baby a direct dose of alcohol through the breastmilk. This direct dose can lead to drowsiness, deeper sleep, weakness, and decreased growth. Babies and adults who have alcohol in their systems may be less able to wake up and respond to stressors in their environment. As a result, babies exposed to alcohol by breastfeeding might not be able to change their breathing to meet their body's needs, especially if they are also overheated, or encounter other risks in the sleep environment.

For resources on maternal alcohol use and SIDS, see **Appendix 5**.

**In general, a breastfeeding mother should not drink alcohol.**

If a mother decides to drink alcohol despite breastfeeding, you might want to suggest that she wait until after the alcohol has cleared her system before she feeds and cares for the baby. Depending on a mother's weight and other factors, it can take as long as 18 hours after drinking for the alcohol to leave the mother's body. You could also suggest that the mother

use a breast pump to express and store milk ahead of time, so that the baby can have stored alcohol-free milk until the mother's body is free of alcohol. The safest option for the baby is for the mother not to drink at all while she is breastfeeding. Mothers and families should talk with a lactation consultant or other health care provider about concerns related to drinking alcohol and breastfeeding.

For resources on breastfeeding, see **page 22**.

## Commercial Tobacco Use

Smoking clearly impacts not only risk for SIDS, but also overall health of the mother and baby in the form of higher risk for other problems, including cancers and lung problems.

### *Smoking During Pregnancy*

One of the most important things a mother-to-be can do for her baby is to not smoke cigarettes or use other commercial tobacco products during pregnancy. Infants of mothers who smoked during pregnancy are up to four times more likely to die of SIDS than children whose mothers did not smoke during pregnancy.

Tobacco use during pregnancy can decrease the amount of oxygen the baby gets. This situation could decrease growth and function in the baby's brain, nerves, and other organs as they develop. Tobacco use during the last half of pregnancy can cause changes in the baby's brain that affect his or her ability to wake up and his or her ability to adjust breathing, heart rate, and control of movements. These changes could place the infant at higher risk for SIDS. In addition, pregnant women who smoke are at higher risk for pregnancy loss, preterm labor and birth, and having a low birth weight infant.

For resources on commercial tobacco use and SIDS, see **Appendix 5**.

**Women should not smoke during pregnancy.**

### *Smoke in the Infant's Living Environment*

Research estimates that commercial tobacco smoke includes more than 4,000 chemicals in addition to nicotine, the chemical most people know about. Scientists have identified more than 250 chemicals in tobacco smoke that are toxic (harmful or deadly). Tobacco use in the home or around the baby exposes the infant to second-hand nicotine and toxic chemicals. Infants whose caregivers smoke or who are exposed to second-hand smoke are at four times greater risk for SIDS than are infants whose caregivers do not smoke. In addition, infants who died of SIDS had higher nicotine concentrations in their lungs than infants who died from other known causes.

A great deal of data indicates that infants who live in households where someone smokes are more likely to have respiratory infections, asthma (a serious breathing problem that can be life threatening), ear fluid problems, and more hospitalizations than those who live in smoke-free households. Second-hand smoke is especially hard on infants and children because their lungs and body systems for removing such toxins are still developing.

A lesser-known result of smoking is that it reduces an adult's ability to wake up. It also increases the risk of *sleep apnea*, a condition in which a person does not get enough air into the lungs during sleep. People with sleep apnea often snore loudly, pause in their breathing for several seconds, and then start normal breathing with a snort or choking sound. Sleep

apnea is a known risk factor for cardiovascular disease (a group of problems related to the heart and blood vessels), but it also lowers the quality of sleep for those who have it. Lost or poor-quality sleep resulting from apnea can sometimes make it difficult for an adult to care for a baby during the night or to stay alert during the day.

**Parents should not smoke or allow others to smoke around the baby.**

## Bed Sharing

Even though bed sharing between an infant and an adult(s) is common, especially in certain cultures, the practice is hotly debated. On the one hand, research evidence shows that bed sharing can greatly increase the risk of SIDS, and that it is quite dangerous in certain situations. On the other hand, mothers and caregivers feel that bed sharing makes bonding and breastfeeding easier.

The research evidence related to bed sharing and SIDS risk shows a clear increase in overall risk and a significant risk increase in specific situations. For instance, *SIDS risk is significantly higher when an infant*:

For resources on bed sharing and SIDS, see **Appendix 5**.

- Shares a bed with other children; or
- Is placed on a sofa to sleep; or
- Sleeps in a bed with a mother who smokes cigarettes; or
- Sleeps in a bed with an adult who has been drinking alcohol; or
- Is younger than 11 to 14 weeks of age; or
- Sleeps in a bed with more than one bed sharer (more than one adult or sibling), especially if the infant is sleeping between two adults.

**Because of this evidence, the AAP Task Force recommends that babies be placed in a sleep area close to but separate from where others sleep.**

Some people suggest that bed sharing makes breastfeeding and bonding easier. Indeed, one study found that babies who bed share and breastfeed wake up more often, which may prevent the infant from going into the deep sleep linked to SIDS risk. However, the risks seem to outweigh any benefits that bed sharing may provide, especially in any of the situations listed above. Having baby's sleep area in the same room as the parents, even right next to the bed in a bedside co-sleeper (a separate infant sleep area that attaches to an adult bed), as shown on left, or another safe sleep area, makes it easy to breastfeed and to touch the infant during the night while still reducing the SIDS risk. Studies have shown that room sharing with the parents decreases the risk of SIDS.

Many people believe that bed sharing reduces SIDS risk because the adult or bed sharer will be able to hear any problems with the infant and to take action more quickly. However, there is no evidence to support this claim. If the bed-sharing situation is like any of those listed earlier, then the risk for SIDS is known to be greater.

Chapter 2 of this Workbook explains more about bed sharing and SIDS risk.

## Stomach Sleeping

Stomach sleeping carries between 1.7 times and 12.9 times the SIDS risk of back sleeping, depending on other factors.

Exactly how stomach sleeping might lead to SIDS is not known. Studies suggest that stomach sleeping may increase SIDS risk through a variety of mechanisms. Stomach sleeping could:

- Increase the likelihood of re-breathing exhaled breath, which is high in carbon dioxide and low in oxygen;
- Block or obstruct in the upper airway; or
- Get in the way of the body's ability to cool itself, leading to overheating.

When compared to infants placed on their backs to sleep, infants who sleep on their stomachs:

- Are less reactive to noise;
- Experience sudden drops in blood pressure and heart rate control; and
- Experience less movement, difficulty waking up (sometimes called a high arousal threshold), and longer periods of deep sleep.

All of these characteristics may put an infant at higher risk of SIDS.

**The single most effective action that parents and caregivers can take to lower their baby's SIDS risk is to place the baby on his or her back to sleep for naps and at night.**

Whatever the mechanism, evidence from numerous countries, including New Zealand, Sweden, and the United States, shows that placing babies on their backs to sleep results in a major decline in the SIDS rate compared to placing babies on their stomachs to sleep. The simple act of placing infants on their backs to sleep significantly lowers SIDS risk and can save infant lives.

## Soft Sleeping Surfaces and Loose, Fluffy Bedding

Sleep surface and bedding are an important but often overlooked risk factor for SIDS.

It makes sense that a soft sleep surface and loose bedding would be dangerous in terms of risk for SIDS or suffocation if an infant is placed on the stomach to sleep. Infants' muscles are not well developed enough to move the face or nose/mouth if they become blocked in soft surfaces or by loose bedding. And, in fact, multiple studies have found the combination of stomach sleeping and soft sleep surfaces and/or loose bedding to be very hazardous.

But research also shows that soft sleeping surfaces and loose, fluffy bedding are strong risk factors for SIDS even among babies placed on their backs to sleep. The same result was found for infants placed on their backs to sleep on adult beds. It is unclear what the mechanism might be or why the risk is higher on soft sleep surfaces; some theories suggest the baby's airways are constricted if it lies "in" the surface rather than on top of the surface. Loose bedding, fluffy bedding, and other soft or stuffed objects in the sleep area can increase SIDS risk because they could end up covering the baby's face and head.

In the 1970s, the Consumer Product Safety Commission (CPSC) began setting safety standards for different crib features, such as minimizing the space between slats and ensuring that the mattress fits snugly into the crib frame. In 1998, the CPSC, in collaboration with the NICHD and AAP, issued a safety alert to tell parents and caregivers to place infants to sleep on a firm crib mattress and to remove all soft bedding from the crib. A few years later, the CPSC began setting standards for the firmness or softness of crib mattresses. Such "safety-approved" cribs are recommended to ensure a safe sleep environment. For more information on crib safety, visit the CPSC Web site at ***http://www.cpsc.gov/info/cribs/index.html***.

Parents and caregivers should avoid placing infants to sleep on any soft surfaces, including those not related to a crib, such as couches, armchairs, sofas, waterbeds, and adult mattresses (which are usually softer than crib mattresses). Placing baby to sleep on quilts, sheepskins, or pillows, even on top of a safety-approved crib mattress, also increases the risk for SIDS.

**Parents and caregivers should place their baby to sleep on a firm sleep surface, such as on a safety-approved crib mattress, covered by a fitted sheet and free of any soft toys or loose bedding. This is the safest sleep environment for baby.**

## Chapter 2:
# Reducing the Risk of SIDS

### Objectives

By the end of this chapter the learner will be able to:

- Define actions that can reduce an infant s risk for SIDS, including those that address risk factors more common among AI/ANs.
- Identify alternative sleep surfaces, including cradleboards.
- Explain ways to lower SIDS risk associated with infant sleep location.
- Describe situations that may improve infant outcomes and further reduce the risk for SIDS.
- Explain Tummy Time and why it is important for infant health.

## Lowering the Risk of SIDS

Even though SIDS is not completely preventable and there is no way of knowing which babies might die of SIDS, there are things parents and caregivers can do to reduce the risk of SIDS, including:

- **Always place the baby on his or her back to sleep for naps and at night.** The back sleep position is the safest, and every sleep time counts.

- **Place the baby to sleep on a firm sleep surface, such as on a safety-approved* crib mattress, covered by a fitted sheet.** Never place the baby to sleep on pillows, quilts, sheepskins, or other soft surfaces.

- **Keep soft objects, toys, and loose bedding out of the baby's sleep area.** Don't use pillows, blankets, quilts, sheepskins, or pillow-like crib bumpers in the baby's sleep area, and keep all items away from the baby's face. If you choose to use a blanket, place the baby with his or her feet at the end of the crib. The blanket should reach no higher than the baby's chest. Tuck the ends of the blanket under the crib mattress to ensure safety (see *page 9* for an example of "feet to foot").

- **Do not smoke during pregnancy and do not allow smoking around the baby.** Don't smoke before or after the birth of the baby, and don't let others smoke around the baby.

- **Do not drink alcohol during pregnancy or when breastfeeding.** Alcohol use during pregnancy is a known cause of both physical and mental problems, including permanent brain damage, developmental delays, and increased risk of SIDS. Infants can also be exposed to alcohol through breastmilk, so women who are breastfeeding should not drink alcohol.

- **Keep the baby's sleep area close to but separate from where you and others sleep.** The baby should not sleep in a bed or on a couch or armchair with adults or other children, but he or she can sleep in the same room as adults or other children. If you bring the baby into bed with you to breastfeed, put him or her back in a separate sleep area, such as a bassinet, crib, cradle, or bedside co-sleeper (an infant bed that attaches to an adult bed) when finished.

- **Think about using a clean, dry pacifier when putting the baby to bed,** but don't force the baby to take it. If breastfeeding, wait until the baby is one month of age or is used to breastfeeding before trying a pacifier.

- **Do not let the baby get overheated during sleep.** Dress the baby in light sleep clothing only, and keep the room at a temperature that is comfortable for an adult.

**Appendix 2** of this Workbook includes a handout of these safe sleep recommendations that you can copy and give out during *Healthy Native Baby Project* gatherings and events.

You can also use the *Healthy Native Baby Project* Toolkit Disk to create your own safe sleep materials, with language and images specific to your intended audience and IHS Area.

* For information on crib safety, contact the Consumer Product Safety Commission at *http://www.cpsc.gov* or at 1-800-638-2772, or talk to your health care provider.

- **Avoid products that claim to reduce the risk of SIDS or to safely position the infant** because most have not been tested for effectiveness or safety. Avoid products made of foam rubber or of visco-elastic polyurethane foam (also known as Memory Foam™).

- **Do not use home monitors to reduce the risk of SIDS.** If you have questions about using monitors for other conditions, talk to your health care provider.

- **Reduce the chance that flat spots will develop on the baby's head.** Provide Tummy Time when the baby is awake and someone is watching; hold the baby upright when he or she is not sleeping; change the direction that the baby lies in the crib from one week to the next; and avoid too much time in car seats, carriers, and bouncy seats. (See the additional information about Tummy Time on *page 25*.)

- **Other things that improve infant outcomes and that may reduce SIDS risk include:** breastfeeding; getting early and regular prenatal care and preconception care; and having Public Health Nurses visit the home.

The rest of this chapter describes some of these risk-reduction strategies in more detail and includes ways to address related issues more common in AI/AN communities.

## Back Sleep Position

**The single most effective action that parents and caregivers can take to lower their baby's risk for SIDS is to always place the baby on his or her back to sleep for naps and at night.**

Researchers do not know exactly how back sleeping is protective, but studies from all over the world have shown that babies are safer sleeping on their backs. Researchers established the link between stomach sleeping and SIDS by observing dramatic decreases in SIDS rates in countries where public health campaigns to reduce stomach sleeping have been successful. In areas where stomach sleeping is rare (such as Hong Kong), SIDS rates are historically very low, which further strengthens the association.

### Every Sleep Time Counts

Research shows that infants who are used to sleeping on their backs, but who are then placed to sleep on their stomachs or sides, are at greatly increased risk of SIDS—greater than the increased risk of infants who are always placed to sleep on their stomachs or sides. One study found that if an infant who was usually placed to sleep on his or her back was then placed to sleep on his or her stomach or side, his or her SIDS risk was *seven to eight times greater* than that of an infant always placed to sleep on the stomach or side. Make sure caregivers tell everyone who cares for baby to always place the baby to sleep on his or her back—for every sleep time.

## How to Counter Fears of Choking

Many parents and caregivers fear that babies placed on their backs to sleep are more likely to choke on spit up or vomit. Because of this fear, they might not place the baby on his or her back to sleep. It's important to address this fear head on with the following fact: *There is no evidence that choking is more common among healthy babies sleeping on their backs than among healthy babies sleeping on their stomachs.*

Cases of fatal choking are very rare, except when the infant had an underlying or associated medical condition. In most of the few reported cases of death due to choking, the infant's sleep position at death, when known, was *on the stomach.*

Babies might actually clear vomit and other secretions better when placed on their backs. The figures below show the location of the trachea and the esophagus in the back sleeping (*Figure 7A*) and stomach sleeping (*Figure 7B*) positions. When a baby is in the back sleeping position, the trachea (airway or windpipe) lies on top of the esophagus (gullet or tube to stomach). Anything thrown up or refluxed from the esophagus must work against gravity to reach the trachea. When a baby is in the stomach sleeping position, anything thrown up or refluxed will pool at the opening of the trachea, making it easier for the baby to choke.

*Figure 7.*

## Orientation of the Trachea to the Esophagus

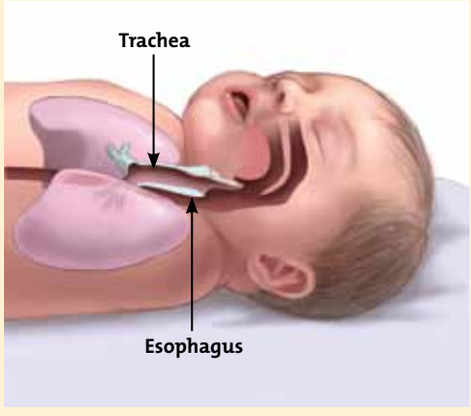



*Figure 7A.*
**Upper-Respiratory Anatomy: Baby in the Back Sleeping Position**

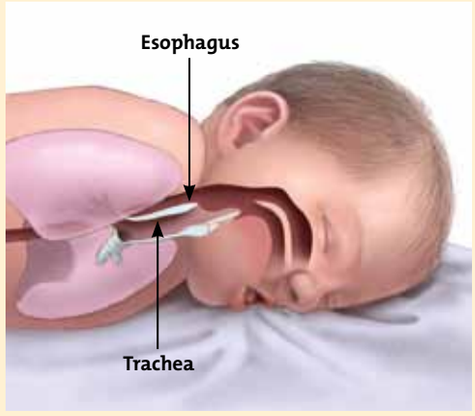



*Figure 7B.*
**Upper-Respiratory Anatomy: Baby in the Stomach Sleeping Position**

# Sleep Surface and Sleep Environment

**Caregivers can reduce SIDS risk by changing features of the infant's sleep environment, such as using a firm sleep surface and removing soft, loose objects from the sleep area.**



## Use a Firm Mattress or Sleep Surface

SIDS risk is lower for infants who sleep on a firm surface, such as a safety-approved* crib mattress covered with a fitted sheet. Infants who sleep on soft surfaces, such as pillows, comforters, or quilts, are at higher risk for SIDS. Caregivers should never place the baby to sleep on pillows, quilts, sheepskins, or other soft surfaces. Similarly, they should not place infants to sleep on waterbeds, sofas, couches, armchairs, or soft mattresses that allow the baby's head to sink in to the surface.

For resources on sleep environment and SIDS, see **Appendix 5.**

## Alternative Sleep Surfaces

Even if families don't have access to cribs or bassinets for their babies, **alternative sleep surfaces** (*Figure 8*) are readily available for little or no cost. For example, if put together well and not covered with thick blankets, sheepskins, or comforters, any of the following can provide firm sleep surfaces:

- Sturdy, laundry-type basket with a smooth, firm bottom
- Heavy, reinforced cardboard box or carton
- Dresser, kitchen, or desk drawer
- Metal or plastic basin with a flat bottom, such as a washtub

*Figure 8.*
### Alternative Sleep Surfaces

These sleep surfaces need little covering, such as a pad or a thin blanket that will not bunch up. For example, wrap a light blanket around a sturdy piece of cardboard and use strong tape or safety pins on the bottom to secure the blanket. That is all the covering needed for a firm sleep surface.

One of the safest alternative sleep surfaces is the **cradleboard**. Native Americans may have originated the concept of *Back to Sleep* with the traditional use of the cradleboard. Although the specific design of a cradleboard differs from Tribe to Tribe, it is essentially a handmade, framed, flat basket where the baby spends much of his or her first year. The baby is placed on his or her back and swaddled into place in this safe and secure environment. Native teachings

*For information on crib safety, contact the Consumer Product Safety Commission at *http://www.cpsc.gov* or at 1-800-638-2772, or talk to your health care provider.

say that cradleboards keep the baby safe in a distinct location, help with the child's skeletal development, strengthen neck muscles, and provide an opportunity for the infant to be visually and emotionally stimulated by his or her environment and family.

## Gifts That Can Increase Risk

Giving gifts is a thoughtful and caring way to celebrate the birth of a baby. But some gifts can also increase the risk for SIDS. Caregivers should use good judgement when deciding whether or not to use a gift. Some items that increase SIDS risk include: very soft sheets, quilted crib sheets, plush or velour crib sheets, sateen crib sheets; infant pillows; crib wedges and sleep positioners; fleece infant wraps; plush sheet savers; and quilted mattress pads. To reduce the risk of SIDS, babies should always be placed to sleep on their backs on a firm surface, free of soft or loose items, for all sleep times.

Instead of using a thick gift blanket with the baby, caregivers may want to hang the gift blanket on a wall as decoration, use it as a window covering in the baby s room, or use the blanket for adults or older children in a living area. This way, caregivers can show appreciation for the gift without increasing baby s SIDS risk.

Because the rates of infant death and SIDS are high in many AI/AN communities, using cradleboards is a good way to keep babies safe. When swaddling a baby for the cradleboard, make sure the baby does not overheat. A light blanket may be all that is needed to keep the baby safe and comfortable. The photos above are examples of an infant ready for cooler or colder air temperatures.

Many Tribes and urban Indian community centers offer classes on how to make and use cradleboards. Additional information and resources related to making and using cradleboards are provided in Chapter 3.

### Remove Soft Objects, Loose Bedding, Toys, and Padded Bumpers from the Sleep Environment

Caregivers should remove pillows, blankets, quilts, comforters, sheepskins, and pillow-like crib bumpers from the baby's sleep area. All items, including blankets, should be kept away from the baby's face.

The most current research shows that crib bumper pads or padded bassinets are dangerous and can cause death or injuries to babies. Before crib safety was regulated, the spacing between the slats of the crib sides posed a danger to babies. At the time, padded crib bumper pads protected the baby from these dangers. Now that crib construction is regulated and must conform to safety standards, the bumper pads are no longer needed and actually carry their own dangers.

In a study published in the *Journal of Pediatrics*, researchers examined several databases maintained by the government's CPSC. The databases tracked deaths and injuries related to cribs and bumper pads. Researchers found three types of deaths when bumper pads were

against bumper; suffocation from baby wedged between bumper and another object; and strangulation from bumper tie around baby's neck. They also found several non-fatal injuries related to crib bumper pads. Because the bumpers prevent only minor injuries and can actually cause injury and death, the researchers concluded that bumper pads should not be used in infant cribs.



## Sleep Location

**The AAP Task Force recommends that infants be placed in a sleep area close to but separate from where others sleep.**

Placing a crib, bassinet, or cradleboard in the same room or sleep area as the parents allows the baby to be safely nearby and easy to reach for breastfeeding or other close contact.

Another option is to use a co-sleeper or bedside sleeper (infant sleep area attached to an adult bed) to allow for close touch and easy access to the baby.

### Bed Sharing

As explained in the previous chapter, bed sharing can increase the risk for SIDS, especially when the infant: shares a bed with other children; is placed on a sofa to sleep; sleeps in a bed with a mother who smokes cigarettes; sleeps in a bed with an adult who has been drinking alcohol; is younger than 11 weeks to 14 weeks of age; or sleeps in a bed with multiple bed sharers (more than one adult or sibling), especially if the infant is sleeping between two adults.

When discussing bed sharing, keep in mind that the AAP recommends that a sleep area close to but separate from where others sleep is the safest sleep environment. Based on the evidence, bed sharing is always riskier than not bed sharing in terms of SIDS, accidental suffocation or smothering, and other accidental or unknown causes of injury and death.

Caregivers must balance the dangers and benefits of bed sharing and take appropriate action to reduce the risk of SIDS and other causes of injury and death. You can help parents and caregivers create a safe sleep environment in the following ways:

- Assess parents' beliefs.
- Determine what risk factors are present in the environment.
- Provide education on known risk factors.
- Show parents ways to make sleep environments safe.
- Help parents reduce their baby's risk through individualized counseling and demonstration.

Parents should always be told about the dangers of bed sharing. If parents choose to bed share, make sure they follow other safe sleep practices to *reduce the risk of SIDS*. For instance:

- Always place baby on his/her back to sleep (for naps and at night).
- Never sleep with the baby on an armchair, couch, sofa, or waterbed.
- Remove soft items (such as pillows, soft covers, toys, sheepskins, quilts, comforters, etc.) from the sleep area.
- Use only light sleep clothing on the baby.
- Do not cover the baby with adult bedding.

Some health care providers in AI/AN communities suggest that the following actions *might reduce the risk of accidental suffocation*. Remember, though, that the safest option for baby is a sleep area close to but separate from where others sleep.

See the *Healthy Actions for Native Babies* Handout in the back inside pocket of the Workbook for more information.

- Move the bed away from walls and other furniture so that the baby cannot become trapped between the mattress, bed frame/furniture, and the wall.
- Place the mattress low to or on the floor.
- Place the baby in the area of the bed just above where an adult's head is.
- Do not allow siblings, other children, or pets in the bed.

## Other Ways to Improve Infant Health and Possibly Reduce SIDS Risk

In addition to the risk-reduction strategies explained earlier in this chapter, parents and caregivers can do other things to help improve their babies' health that may also help protect against SIDS. Researchers are still gathering scientific evidence about these additional practices, but some findings show that babies benefit from these actions.

### Breastfeeding

Breastfeeding, also called nursing, can be an easy and less expensive way for a mother to feed her child.

For resources on breastfeeding, see **Appendix 5.**

According to the 2005 AAP Policy Statement on Breastfeeding, women who don't have health problems should exclusively breastfeed their infants for at least the first six months of life. The AAP suggests that women try to breastfeed for the baby's first 12 months of life because of the benefits to both mother and baby. Women can breastfeed after their baby is one-year old, if it is something that both mother and baby want to do.

Breastfeeding offers many benefits to the baby. For example:

- Breastmilk provides the right balance of nutrients to help an infant grow into a strong and healthy toddler.
- Breastfed infants are less likely to die during their first year and experience fewer illnesses than babies who are fed formula.
- Some of the nutrients in breastmilk also protect an infant against some common childhood illnesses and infections, such as diarrhea, middle ear infections, and certain lung or respiratory infections.
- Some recent NICHD-supported research also suggests that breastmilk contains important building blocks for brain development and growth. Two specific building blocks, the fatty acids known as DHA and AA, may help increase infants' cognitive skills. Many types of infant formulas available in the United States are fortified with DHA and AA. All formula available for preterm infants is fortified with these building blocks.

Some studies also show that breastfeeding is associated with a lower risk of SIDS.

Some women, such as those with certain chronic health problems, including HIV, are advised not to breastfeed their infants. If your client has a health problem, suggest that she discuss breastfeeding with her health care provider.

The decision whether or not to breastfeed is a private one that takes into account personal, family, professional, and economic issues. Every woman's reasons for breastfeeding or bottle feeding are her own. You should always respect that decision.

If a mother stops breastfeeding before the child is one-year old, or decides to bottle feed from the infant's birth, then she should feed her infant iron-fortified commercially available formula. Health care providers advise women not to give their infants cow's milk until the child is at least one-year old.

## Resources Related to Breastfeeding

There are many excellent programs ongoing around the country that promote and support breastfeeding. To obtain information, assistance, and/or resources related to breastfeeding or lactation support in your local area, contact one of the following resources:

- Women, Infants, and Children (WIC) office: ***http://www.fns.usda.gov/wic/Breastfeeding/breastfeedingmainpage.htm***
- La Leche League International Group: ***http://www.lllusa.org/groups.php*** (to get information specific to your state)
- Local hospital obstetric unit
- Pediatric clinics
- Support programs, such as Healthy Families (***http://www.healthyfamiliesamerica.org***)

## Prenatal Care

Prenatal care is the care woman gets before her baby is born. Getting early and regular prenatal care improves the health and outcomes of mothers and babies (see the *Planning Pregnancy and Preconception Care* sidebar on the next page). Prenatal care includes health care, along with education and counseling about how to handle different things related to pregnancy and parenting.

Prenatal care is a primary way to help to identify and treat issues or concerns before they become full-blown health problems. Research also shows that not getting early or regular prenatal care is associated with SIDS. Health care providers encourage women to get early and regular prenatal care as yet another way to possibly lower SIDS risk.

During prenatal care, a health care provider will talk with the woman about many issues, such as nutrition and physical activity, what usually happens during childbirth, and basic skills in infant care. Providers also watch the growth of the developing fetus as a way to detect and, if possible, treat problems that could lead to low birth weight, which is a risk factor for SIDS by itself. These providers also watch for signs of early labor as a way to prevent preterm birth, which is also a risk factor for SIDS by itself.

Prenatal care also teaches pregnant women and their families some basics about caring for themselves and

the baby. Providers discuss situations that increase the risk for SIDS, such as drinking alcohol, using tobacco, and unsafe sleep environments. Recent research suggests that some of the brain defects associated with SIDS may be influenced by or result from prenatal exposure to toxins, such as alcohol and tobacco. Getting early and regular prenatal care is a powerful way to improve an infant's chances for a healthy life and to reduce the risk for SIDS.

## Planning Pregnancy and Preconception Care

Most health care providers suggest that women plan their pregnancies as a way to improve their health and the health of their babies.

Many health care providers recommend that women see a health care provider for *preconception care*, care received before even trying to get pregnant. During this type of care, the patient and the health care provider can talk about things that can improve not only the chances of getting pregnant, but also the likelihood of healthy pregnancy. These things include:

- Avoiding alcohol, illicit drugs, and smoking
- Getting recommended vaccinations/immunizations
- Maintaining a healthy weight or, if needed, losing weight
- Improving nutrition, taking vitamins, and getting enough folic acid

For more information, visit the NICHD Web site at ***http://www.nichd.nih.gov/health/topics/preconception_care.cfm***.



## Public Health Nurse (PHN) Visits

Results from the Aberdeen Area Infant Mortality Study, which involved AI/ANs from the Northern Plains, found that infants were less likely to die of SIDS if their mothers received visits from a PHN during pregnancy and after giving birth. A visit from a PHN reduced SIDS risk by one-fifth compared to babies who did not receive such attention. In light of these results, study leaders recommended "strengthening PHN programs" and community-based programs, such as Healthy Start, to provide the extra attention that AI/AN communities need to further reduce the risk for SIDS.

PHNs provide many important services to families. Because the PHN comes into a family's home, family members may be more comfortable interacting with the PHN and may be more likely to trust him or her than another type of provider, seen outside the home.

During the visit, the PHN can:

- Assess and provide guidance about the safety of the home environment.
- Allow parents to ask questions and address concerns that they may have been shy about or forgotten to ask in an office, clinic, or hospital setting.
- Provide guidance about infant health and development.
- Offer reality-based suggestions, interventions, and referrals as needed.

For resources on PHN visits and SIDS risk, see **Appendix 5.**

You should suggest that families schedule regular visits from a PHN both during pregnancy and after the baby is born, if these visits are available in their area.

# Make Time for Tummy Time!

**Encourage parents and caregivers to provide lots of Tummy Time, placing babies on their stomachs when they are awake and someone is watching them.**

Tummy Time is a necessary and very important part of a baby s healthy development of motor skill and brain functions. Among its many benefits, Tummy Time:

- *Reduces the risk of flat spots developing on the back of the baby' s head.* Infants skulls are made up of several bones that are free-floating during the first few months of life so the brain can grow. Back sleeping may cause flat areas on the back of the infant s head. These flat areas are usually not dangerous and typically go away once the infant starts to sit up on his or her own. There is no evidence that this flattening is harmful or that it is associated with permanent problems with head shape. Tummy Time decreases the chance that such areas will form. Other ways to reduce the chance of flat spots include:

  - Changing the direction the baby s body is placed in the crib or bed (see *Figure 9*) Because babies naturally turn toward light or activity, changing how they lay in the crib can reduce the pressure on one specific area
  - Holding the baby upright sometimes called cuddle tim e when he or she is not sleeping
  - Limiting the amount of time spent in free-standing swings, bouncy chairs, car seats, and carriers
- *Promotes muscle and motor development.* An infant lying on the stomach while awake and being watched is strengthening his or her neck and shoulder muscles. Strong neck and shoulder muscles can help babies reach motor development milestones. Tummy Time gets baby s body ready to sit up, slide on the belly, and crawl. As babies grow older and stronger, they actually need more Tummy Time to build enough strength to support their own bodies when they try standing and, later, walking.

*Figure 9.*

Advise parents and caregivers to let infants have two, three, or more short Tummy Time sessions throughout the day. After a diaper change or after the baby wakes up from a nap are ideal times for Tummy Time. Having a toy or toys in reach can help babies learn to play and interact with their surroundings. Having a parent, caregiver, or sibling nearby during Tummy Time is also a great way to bond with the baby.

Some babies may not like the tummy position at first, but most take to it after just a few sessions. Make sure all family members know about the importance of Tummy Time, and suggest ways to make it a safe and fun part of the family s time together. After some practice, babies and families can enjoy all the benefits of Tummy Time.

For more information on Tummy Time, visit the NICHD Web site at ***http://www.nichd.nih.gov/health/topics/Tummy_Time.cfm.***

## Chapter 3:

# Strategies for Reaching Communities Know Your Audiences

### Objectives

By the end of this chapter the learner will be able to:

- Describe primary and secondary audiences for safe sleep messages and suggest some options for where and when to reach out to them.
- Understand the risks associated with unaccustomed sleep position and its relationship to child care settings.
- Describe essential behaviors for health and service providers to use while interacting with AI/AN patients and clients.
- Define hard-to-reach and underserved audiences and identify ways to reach them.
- Identify ways to reach out to families who have experienced loss of a child from SIDS or another cause.

## The Importance of SIDS Education

Now that you know a little bit about SIDS, its common features, and ways to reduce the risk, let's think about how to reach out to others with this information. To begin, who needs education about SIDS and SIDS risk-reduction strategies?

**The answer is: Everyone needs education about SIDS and SIDS risk reduction.**

Parents, grandparents, foster parents, family members, health care providers, day care/child care providers, emergency responders, and others of all ages need to know the risks for SIDS and the ways to reduce those risks.

To be truly effective, everyone in the community and in a baby's environment needs to know the ways of reducing SIDS risk and *needs to practice the risk-reduction strategies consistently*. Consistency—using these same practices time after time—can save infant lives. Remember that infants who are usually placed to sleep on their backs, but who are then placed to sleep on their stomachs—even for a single nap—are at greatly increased risk for SIDS. For this reason, consistency is critical—infants should be placed to sleep on their backs for every sleep time, for naps and at night.

For resources on SIDS and reducing SIDS risk, see **Appendix 5**.

To be a good communicator, it is important to know your audiences, where you can reach them, and how you can reach them. The rest of this chapter helps to define the various audiences that you may need to reach, describes where you might be able to reach them, and suggests ways to reach out to them.

## Who are the primary audiences?

### Parents and Parents-to-Be

Parents and parents-to-be are the first critical audience for SIDS education. Because they are the primary caregivers and decision makers for their infants, parents and parents-to-be need to learn about the risks for SIDS and about ways to reduce those risks. This education is a main step in any type of SIDS outreach.

Sharing information about safe sleep guidelines can give parents effective tools for protecting their children, while also giving them the confidence to raise healthy children. An educated parent can also correct SIDS misinformation and counter SIDS myths, which may be common within the community.

#### *Where can you reach them?*

In addition to during regular health care visits, you can educate parents and parents-to-be during community gatherings, workshops, and health and wellness fairs. In these environments, they have the opportunity to ask questions about safe sleep recommendations so they can better understand SIDS and the research evidence that forms the basis of the recommendations.

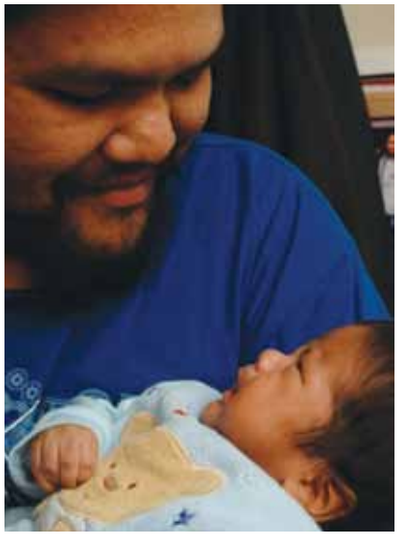
Educational counseling can also include one-on-one sessions with PHNs and outreach workers (such as social workers, community Elders, and health educators). Providers can tailor these sessions to meet the individual needs of parents and families. In addition, home-visiting providers have a unique opportunity to help parents assess risks in the infant's sleep environment and to demonstrate safer sleep practices where the infant actually sleeps.

Parent-to-parent or peer support/activity groups also provide a good forum for education. These types of gatherings are especially useful for reaching teen and new parents, who often seek support from older, more experienced members of the community. By serving as a knowledgeable moderator during meetings of such groups, you can help the group members explore questions and concerns about SIDS risk reduction, safe infant care practices, and SIDS research.

## Use of Fear, Guilt Trips, or Shame to Communicate Health Messages

Even though fear can be an effective way to get attention at first, long-term use of fear is usually not an effective way to change or maintain new and desirable behaviors. Similarly, using shame suggesting or implying that parents are irresponsible or that they don t care enough for the child because of their choices is also a poor way to motivate people to change their behaviors. Instead, put a positive focus on constructive actions that people can take to reduce the risk for SIDS or to improve infant and family health. This approach is not only more caring, but is also a more effective way to create lasting change.





### *When can you reach them?*

During pregnancy and just after the infant is born are good times for educating parents about SIDS risk-reduction strategies. For many women, pregnancy is a good time to think about and make healthy changes. Soon-to-be parents and new parents, especially, are highly motivated to do everything possible to ensure their infant's health and happiness. A lot of times, though, they aren't sure what the "right thing" is when it comes to reducing the risk for SIDS. They may also be getting mixed messages: their family may be telling them one thing about how and where babies should sleep; health care providers may be saying something else; and their friends may have different opinions.

As a health educator working in any setting, you should keep in mind the importance of the following concepts:

- Sharing critical and accurate information
- Approaching parents and others with respect
- Providing empowering messages about how to safely care for infants
- Instilling confidence in parents' ability to reduce the risk of SIDS and protect their children

Parent and parent-to-be education is the key to solving the problem of SIDS.

## Foster Parents and Foster Families

Foster parents and families are an audience with some unique SIDS education needs for a number of reasons:

- They probably did not have the chance to learn about SIDS during pregnancy and right after the baby's birth.
- Foster families with mostly older children are less likely to know current information about reducing SIDS risks.
- In some cases, the factors or environments (such as problems with alcohol) that led to the child being placed in a foster home may be associated with increased SIDS risk.



### *Where and when can you reach them?*

Those who are involved with placing children in foster care, such as maternal and child health service providers and social service and child protection providers, have an important opportunity to educate foster parents before or immediately after a child is placed in the foster home. In many cases, the required follow-up visits offer additional opportunities to assess the infant's sleep environment and to recommend SIDS risk-reduction strategies for the foster home.

This type of education and follow-up is critical for these particularly vulnerable infants. Foster families should be included as a regular audience for any community effort to reduce the risk for SIDS.

## The Community (Elders, Extended Family/Friends, and Youth)

In the context of the importance that Native culture places on community, outreach materials and projects need to extend their messages to address the community as a whole. As part of your efforts in the *Healthy Native Babies Project*, you can offer to share the latest information and evidence-based strategies for reducing SIDS risk with Elders, extended families and friends, and youth in the community.

In many AI/AN communities, **Elders**—particularly older women—are the opinion leaders about childrearing practices. As you begin your outreach efforts, remember the following:

- Gather ideas and wisdom from the Elders. Because the Elders likely know the community better than anyone else, they can play a critical role in developing outreach strategies for the community, especially for those members who are hard to reach.
- Present SIDS risk-reduction strategies to Elders in a way that does not confront or question their authority and knowledge.

- Understand local history when planning activities. Some parents or community Elders may have been raised away from the community (in non-voluntary boarding school or foster family arrangements). As a result, they may lack context for current childrearing practices from their own childhoods.

### *Where and when can you reach them?*

You can reach Elders and seniors through a variety of venues including: senior centers, congregate meal programs, nutrition centers, senior health fairs, senior housing, senior companion programs, Elder committees, and activity days. Many Tribes run U.S. Department of Health and Human Services (DHHS) Administration on Aging Title VI programs. Contact your local Title VI Director to discuss potential collaboration and outreach opportunities. To search for programs in your area, visit the Administration on Aging Web site for Native American Programs at: ***http://olderindians.org***.



Another unique aspect to doing outreach in AI/AN communities is the involvement of **extended family and friends** in various childrearing roles. For example:

- The Native definition of "family" differs from that of most non-Natives. Within AI/AN communities, extended family and friends form unique family units that may differ from those common in non-Native communities.

- Members of the family may play different roles in childrearing that don't match up to the "normal" nuclear-family model. For many AI/AN communities, family responsibilities for childrearing include those traditional for the Tribe, rather than for an individual family.

- Communities may also be a mix of traditional AI/AN families, which include extended family members, and nuclear families.

Make sure your outreach efforts include the entire "family"—including family and friends. Don't be judgmental about the specific form of the family. Keeping an open mind and an inclusive attitude about the variety of family structures, members, and roles your audience might have is also essential.

Many AI/AN communities also have an active **youth culture**, which is often interested in activities that enable them to give something of themselves back to the community. While volunteerism and community service can help young people create their identities—a key developmental task for teens—such activities also provide an excellent forum for outreach about SIDS risk reduction.

# A Critical Primary Audience: Child Care Providers

## Did you know?

- Two-thirds of infants younger than 12 months of age are in child care, defined as care from someone other than the infant s parent, at least some of the time.
- About 20 percent of SIDS deaths in the United States occur in a child care setting, while the infant is under the care of someone other than the infant s parent. Many of these child care deaths are associated with the stomach sleep position, especially when the infant is unaccustomed to being placed to sleep in that position.
- Infants who are usually placed to sleep on their backs, but who are then placed to sleep on their stomachs or sides like for a nap when being cared for by a babysitter are at extremely high risk for SIDS. In fact, the risk is *7 times to 8 times greater* than for infants used to sleeping on their stomachs or sides.

Infants who spend time in day care homes, child care centers, homes of friends or family members, or even their own homes under the care of family, friends, or babysitters can be at significantly higher risk for SIDS if their caregivers are not educated about risk-reduction strategies. Despite the decrease in overall SIDS rates, the proportion of SIDS deaths in child care settings has remained relatively constant since 1992.

Many providers are simply not aware of the back sleeping or other safe sleep recommendations. Others rely on older information or are misinformed about SIDS risks. Research shows that educational programs are effective at increasing knowledge of safe sleep recommendations among child care providers. Such programs might already be in place in your area, through local or state health departments or through the boards that license or regulate child care providers.

Take advantage of existing education programs and offer to share the latest research and safe sleep strategies with the program leaders or the provider audiences. If a program is not currently ongoing in your area, make sure to include this important audience in your *Healthy Native Babies Project* planning and outreach efforts.

**Tell anyone and everyone who cares for a child parents, grandparents, foster parents, aunts, uncles, siblings, babysitters, child care providers to place the baby on his or her back to sleep every time, for naps and at night.**

### *Where and when can you reach them?*

Babysitting classes, youth gatherings, or general health education classes are places where potential teen babysitter or sibling audiences can learn about reducing the risk of SIDS. Community center settings also provide opportunities to reach out to youth who may fall outside the potential babysitter or sibling audience. Empowered with risk-reduction knowledge, youth can become effective partners in your SIDS risk-reduction effort by spreading and practicing the strategies on their own.

## Who are the secondary audiences?



The term "secondary audience" does not mean that groups are less important than the primary audiences described earlier. Instead, secondary audiences include people who do not directly provide care to children, but who interact in different settings with those who do provide direct care. Educating secondary audiences about ways to reduce the risk for SIDS is a good way to reach parents, grandparents, and other caregivers. These secondary audiences can help get your message deeper into the community, in less time.

### Health Care Providers (Doctors, Nurses, Dentists, and Others)

Health care providers often have many opportunities to educate parents and families about SIDS risk and SIDS risk reduction. Providers are not just limited to doctors and nurses, but also include dentists and dental health providers, opticians/eye care providers, pharmacists, home health care workers, and others who may interact with families and with children.

Identifying strategies to increase providers' effectiveness as they educate, motivate, and support parents and caregivers in adopting SIDS risk-reducing practices is an important part of a successful *Healthy Native Babies Project.*

### *Where and when can you reach them?*

Reach out to health care providers at different locations to ensure that they have the most accurate information about SIDS risk reduction. They can help spread safe sleep messages to their patients and clients in the following locations/situations:

- In the hospital, clinic, or birthing center. The hospital setting immediately after the baby's birth provides a perfect place to discuss SIDS risk reduction and to model safe sleep practices for parents and caregivers. Research shows that hospital nursery staff can have a significant impact on parent and caregiver behaviors after leaving the hospital. For example, in one 2002 study, a 30-minute training session for nursery nurses increased understanding of their influence on families and

## Universal Aspects of Care

In most Indian health care settings (i.e., IHS, Tribal, or urban), health care and health education providers are a mixture of local AI/AN people and non-AI/AN providers with diverse ethnic and cultural backgrounds.

There are aspects of the provider/patient relationship that are universal in terms of the providers effective behaviors. In the mid-1990s, IHS conducted a broad-based consumer survey in which several common patient expectations were identified. Based on the survey, patients wanted to be:

- Treated with respect and understanding;
- Listened to/heard; and
- Able to ask and be asked questions and have their questions answered.

helped the nurses to consciously and consistently place infants on their backs to sleep in the nursery. Families reported seeing the nurses place infants on their backs. More importantly, families continued to place their infants on the back to sleep at home.

- During the infant's health care appointments, such as well-baby checkups. It doesn't matter where these sessions take place—in a doctor's office, in a clinic, in the baby's home—these appointments provide a great opportunity to educate and continue educating parents and family about SIDS risk reduction. Doctors, nurses, physicians' assistants, and other providers can explain and reinforce safe sleep messages during these visits.

- During other family health-related appointments. For example, a dentist may not give dental care for a child younger than one year of age, but he or she may spend time caring for the teeth of that child's parents and grandparents. This set-aside time together provides a good opportunity for the dentist to discuss issues related to safe sleep environments and SIDS risk reduction. Pharmacists can also remind families about safe sleep messages when they pick up medicines or other items at the pharmacy or store.

To make the most of every opportunity, make sure you reach out to all types of health care providers with important information about safe sleep strategies. Once these providers know the safe sleep strategies, they can help you get those messages out into the community and reinforce these teachings by talking about the issues consistently and during each encounter.

### Emergency Personnel, First Responders, and Others Involved with the Death Scene

Dealing with a sudden infant death presents both professional and personal challenges for first responders and for those who work in emergency medicine settings. A lot happens during this type of situation. While working to revive the infant, emergency medical staff might also have to console the parents, other caregivers, and family members. At the same time, these personnel might also be assessing and recording information about the death scene to assist with the investigation.

Others—emergency room doctors and nurses, medical examiners, pathologists, and coroners—get involved later in the process to determine how the baby died. Funeral directors, clergy/spiritual leaders, PHNs, and grief or bereavement counselors may also play roles after the death of an infant. It is not surprising that, at times, dealing with and supporting parents and families who have just lost an infant can be overwhelming.

The National Sudden and Unexpected Infant/Child Death and Pregnancy Loss Resource Center offers useful information for first responders, emergency personnel, coroners, funeral

personnel, and others who may be involved with handling the death of an infant. Please visit ***http://www.sidscenter.org/AZtopics.html*** to find information for different audiences. All of these types of personnel can benefit from knowing the information about SIDS and SIDS risk presented in this Workbook. In addition, the Center also provides a fact sheet at ***http://www.sidscenter.org/documents/SIDRC/ProfessionalRole.pdf*** explaining the roles played by various professionals involved when a sudden infant death occurs, possible responses to grief, causes of sudden infant death, and some of the differences between SIDS and child abuse.

Share these handouts and other information with the first responders and other emergency personnel in your community. You might also want to suggest that printed copies of these materials be stored in emergency vehicles. Be sure to include this important secondary audience in your SIDS risk-reduction outreach.



### Other Secondary Audiences

Opportunities to spread safe sleep messages aren't limited to situations related to health care or emergency health care. Any concentrated time with parents and families offers the chance to educate caregivers about SIDS and SIDS risk reduction. Hair dressers, barbers, manicurists, grocery store staff, general store staff, and others can all play important roles in spreading safe sleep messages and in reinforcing safe sleep practices.

Think about where parents and caregivers in your community spend their time, and then reach out to the staff in those locations to help spread the safe sleep messages.

## Critical Steps to Building a Positive Relationship Between Provider and Patient/Client

In addition to the "Universal Aspects of Care" on the previous page, research from other settings has documented patient expectations that may help health care and other providers to connect with their patients and to start building a trusting relationship. Providers can adopt these steps as a standard of care when dealing with patients or clients:

1. **Greet the patient or client by name.** Greet your patients or clients respectfully with the most common local greeting phrases and using the patient's name.

2. **Introduce yourself.** It is important for providers to introduce themselves at the first visit or, if it has been a while since the patient has been seen, at follow-up visits. Providers should keep in mind that the amount of direct eye contact that is culturally appropriate to give and receive varies across AI/AN settings and sometimes by age and gender.

**Parents or caregivers who are dealing with an acute health problem for their child or themselves are not in the best state for receiving new information.** Such times are probably not optimal for addressing SIDS risk-reduction practices. Providers should delay such outreach efforts until the immediate health problems are under control, unless the issue is directly related to SIDS risk.

3. **Provide support and reassurance, and be responsive to patient/client anxiety.** Many people seeking health care are experiencing physical pain and/or fear or anxiety about the future. A first critical step in reassuring the patient/client is to recognize these feelings and to know that he or she may display such feelings through verbal and non-verbal behaviors as the exam or meeting continues. Once a provider recognizes any anxiety or discomfort, he or she should attempt to put patients at ease by being attentive, being expressive through non-verbal means (such as not crossing the arms in front of the body, a pose that could signal one is closed and not listening), and by offering reassurance.

4. **Facilitate dialogue and collaboration.** Critical to this process is asking carefully thought-out and non-judgmental questions in plain language, followed by attentive listening. At this stage of the encounter, providers should be assessing the best way to provide education and assistance.



5. **Respond to, teach, and negotiate desired behaviors.** Based on information gathered during early steps of this process and on the clinical or other assessments made, the provider should attempt to clarify any risks or concerns and explain any options for care to the patient, parent, or family. It is important to avoid "talking down" to patients and to avoid the use of "jargon" words or concepts that may not be familiar to a non-provider. The intent of this dialogue process is to:

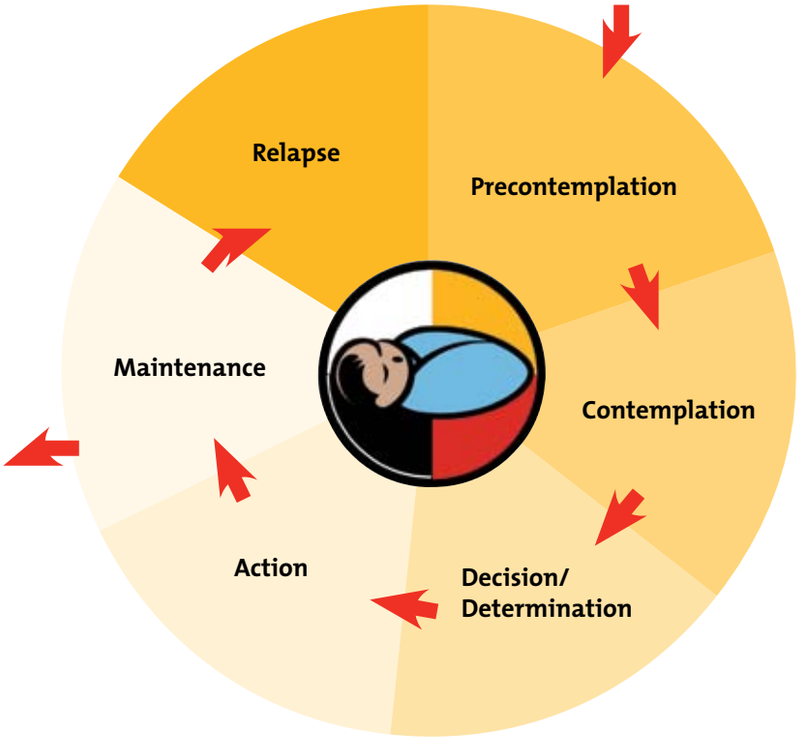
   - Respectfully respond to the perspective of the patient/client;
   - Acknowledge and clarify an understanding of the problem as described, and identify how services can/may be combined with traditional medicine to address or alleviate the problem; and
   - Actively teach patients/clients, with the intent of informing and empowering them to assume appropriate responsibility for their own or their child's health. Such teaching may require the provider to respectfully challenge assumptions, including some scientifically inaccurate ideas, that patients/clients may have about risks or solutions to health problems. For example, a family might be coping with pressure from the child's grandmother to place the child to sleep on his or her stomach. Supplying the family with updated and accurate information will allow the new parents to come to their own decisions about safe child sleep position.

6. **Provide closure to the encounter by expressing a warm and encouraging goodbye.** In addition to giving the patient/client encouragement, this last step offers final chance to ask and to answer any remaining questions. Simply moving on or ending the meeting, without an opportunity for closure, can leave patients emotionally uncertain of their situation or with important questions left unanswered.

Research shows that eliminating any of these steps can have a measurable negative effect on patient/client satisfaction with the service(s). In some cases, skipping a step may also impact compliance with recommendations or treatments. Observations in many public and private health care settings (including IHS settings) have shown that many providers from various

*Figure 10.*

## Stages of Behavior Change Theory






health-related fields frequently miss one or more of these critical steps. Therefore, it is not an overstatement to suggest that following these steps can make a positive difference in the patient/client outcome(s).

To further improve the relationship between providers and patients/clients, providers might want to integrate the "Stages of Change Theory" (*Figure 10*) and other recognized health education approaches into the basic steps listed previously. For instance, the Stages of Change Theory addresses behavior change as a process that occurs over time. Individuals, communities, agencies, etc., may be at different places in their motivation or willingness to change. Identifying where an audience member or group is on the change continuum (see Figure above) allows an educator to better adapt the message or intervention in a way that may more successfully produce behavior change.

In the context of the Stages of Change Theory and other health education approaches, any risk-reduction effort for a selected community or specific audience requires a thorough evaluation of that audience's current beliefs, practices, and fears to begin addressing these issues effectively.

Appendix 3 provides short explanations of many common health education approaches.

## Outreach to Hard-to-Reach and Underserved Populations

Trying to reach those who may have the greatest need for up-to-date health and prevention information can come with unexpected challenges. Hard-to-reach and underserved individuals are often the most stressed, the hardest to find, the least mobile (in terms of transportation), and the least able to follow through with health promotion and disease prevention activities. They are among the most vulnerable groups we attempt to serve.

Several **red flags** might indicate that a family may need more individualized service or education messages:



- Homelessness
- Incarceration or problems with law enforcement system
- Alcohol or substance use/abuse issues
- Psychiatric conditions or depression
- Learning disabilities or cognitive problems, such as FASD
- Late prenatal care or no prenatal care
- History of childhood abuse
- Family violence
- Involvement with child protective services or family services
- History of SIDS or infant death in the family
- Worrisome behaviors displayed/observed
- Families for whom providers/visitors have a "hunch" that help is needed
- Stating that their problems are significant
- Saying that they need help

Visit **Appendix 1** for a list of abbreviations and acronyms and their explanations.

In general, outreach to groups impacted by these types of issues and situations needs to be handled carefully and should respond to a person's or family's specific situation.

One key element of outreach to hard-to-reach groups is going "where they are at," meaning outreach staff may need to challenge their own comfort zones and immerse themselves in new and maybe uncomfortable situations. Before you or your colleagues set out to reach these populations, you may want to do the following:

- Talk with others who already do outreach to these hard-to-reach groups to get ideas for your efforts.
- Be compassionate.

- Be "real."
- Be willing to help the situation at hand.

Another key element of this type of outreach is trying to understand the unique situations of these audiences. Listen to their stories, and keep in mind that there are basic human needs that, if not met, can get in the way of one's ability to thrive. Individuals who have unmet survival or safety needs might find it difficult to really listen to prevention ideas. It may be hard for them to follow through on actions, especially if they don't or can't accomplish, understand, or value such actions. For many in these populations, survival and safety are the priorities—everything else takes second place. The outreach strategy for these audiences needs to include a message that makes sense from their perspectives and that relies on resources they have available to them.



The table below lists organizations that assist and serve many hard-to-reach populations.

## Organizations that Serve Hard-to-Reach Populations

| Organization | Address (Web or Mailing) | Phone |
|---|---|---|
| American Indian Community Center | 905 East 3rd Avenue<br>Spokane, WA 99202 | (509) 535-0886 |
| Anishinabe Wakiagun American Indian Community Development Corporation | http://www.aicdc-mn.org/node/23 | (612) 871-2883 |
| Chief Seattle Club | http://www.chiefseattleclub.org | (202) 292-6214 |
| National Resource Center on Homelessness and Mental Illness (part of the U.S. federal government s Substance Abuse and Mental Health Resources Administration) | http://www.nrchmi.samhsa.gov | (800) 444-7415 |
| Native American Rehabilitation Association of the Northwest | http://naranorthwest.org | (503) 224-1044 |
| Peta Wakan Tipi | http://petawakantipi.org | (651) 646-8167 |
| Tahoma Indian Center | http://www.ccsww.org/site/PageServer?pagename=families_emergencyservices_tahomaindiancenter | (253) 593-2707 |
| United Indians of All Tribes Foundation | http://unitedindians.org | (206) 285-4425 |

The next section describes some ways to reach out to those dealing with "red flag" issues.

## The Homeless

Homelessness is one of several stressful life events than can lead to poor birth outcomes for AI/AN families. The statistics on this topic are cause for concern:

- According to *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*, a 2003 report released by the U.S. Commission on Civil Rights, approximately 90,000 AI/AN families are homeless or under-housed. (The report is available at ***http://www.usccr.gov/pubs/na0703/na0731.pdf.***)

- Pregnancy Risk Assessment Monitoring System (PRAMS) data for Seattle, Washington, collected between 1999 and 2001, indicated 15 percent of new AI/AN mothers reported that they were homeless during the year before delivering their babies. (Public Health-Seattle & King County, *Public Health Data Watch*, Vol. 1, No. 1, Oct. 2004.)

Several national and local organizations across the country serve this hard-to-reach population (see table on *page 39*). You should try to work with the staff of these organizations to provide information to these families.

## The Incarcerated

Incarcerated women—those in jail, prisons, halfway houses, or probationary homes—represent an especially "hidden" population, which deserves access to information and education about SIDS risk reduction. Even though many of these women do not have children living with them in prison, some have infants living with or near them. Others, after release, may suddenly be the sole caregivers for one or more children. By providing risk-reduction messages and education to these women, you can empower them to care for themselves and for their babies and families. You can also reach out to the caregivers of the women's children, such as foster parents, grandparents, and other family members, to help ensure consistency of care.

Keep in mind the following as you conduct outreach with this population:

- Rates of incarceration for indigenous people are usually higher than for other populations.
- Women of color, including AI/AN women, are generally over-represented in the prison population.
- Rates of domestic abuse and violence are often high among AI/AN women, and statistics show a close relationship between abuse and incarceration among AI/AN women.
- Many Native women are lumped into the "other" category, along with Native Hawaiians and Pacific Islanders, for state-level data about incarceration rates. This type of categorization could increase Native women's feelings of being unimportant.

The table below lists resources related to working with those who are incarcerated.

## Resources Related to Working with Incarcerated Populations

| Organization | Internet Address | Phone/E-mail |
|---|---|---|
| Critical Resistance | http://www.criticalresistance.org | (510) 444-0484 |
| Defending Justice: An Activist Resource Kit (From Political Research Associates) | http://www.defendingjustice.org | (617) 666-5300 |
| Incite! Women of Color Against Violence | http://www.incite-national.org | (484) 932-3166 |
| Partnership for Safety and Justice (Formerly the Western Prison Project) | http://safetyandjustice.org/programs/prison-program | (503) 335-8449 |



## Individuals Impacted by Cognitive Problems and Fetal Alcohol Spectrum Disorder (FASD)

Because alcohol is a legal substance that is used widely in American culture, and because more than 45 percent of pregnancies in the United States are unintended, many women expose their fetuses to alcohol without knowing it and without meaning to do so. As explained in Chapter 1 of this Workbook, alcohol use during pregnancy is known to cause both physical and mental problems, including permanent brain damage and developmental delays. The true impact of alcohol exposure is often not known until a child develops behavioral problems or learning disabilities. Those exposed to high amounts of alcohol or exposed on a regular basis may have problems related to FASD, also known as Fetal Alcohol Syndrome (FAS).

FASD is often considered a "hidden" problem because the brain is the organ most affected but you can't "see" the problems, and because the symptoms might be subtle or hard to detect. Most people with FASD have normal intelligence, but they may miss social cues and signals that help others with social interactions. Many people impacted by FASD are also not diagnosed, or are not diagnosed in a way that supports them or helps them to interact with and understand the world around them. As a result, many people with FASD also have secondary problems, including (but not limited to): mental health issues, disrupted school experience, trouble with the law, time in jail or a treatment program, inappropriate sexual behavior, and alcohol or drug problems.

FASD poses lifelong challenges and problems, but these can be reduced with individualized support and the right environment. These problems can be more troublesome in a family situation because more than one generation may be dealing with the challenges of FASD.

In the context of SIDS education, you may need to adjust how you provide information to clients impacted by FASD. You may need to rely on "external brain strategies," which allow individuals to use sensory and reminder devices and practices to accomplish daily tasks. For example:

- Many clients with FASD may not be able to remember information from day to day. To educate persons with this problem, you may need to provide clearly written, step-by-step lists to help them remember risk-reduction tasks. Or, they may respond to more visual signals, such as a sheet showing safe sleep environments.

- Demonstrating and modeling correct risk-reduction actions may also be useful for those with FASD.

- Displaying visual reminders and step-by-step actions in very visible places within the home (such as on or near the baby's sleep area) may also help remind caregivers of the steps they can take to reduce SIDS risk.

- Reinforcing correct actions is also critical for outreach to these individuals. In some cases, this reinforcement and encouragement may need to come from someone close to the caregiver who can give advice and provide oversight. Someone in the baby's environment can fill such a role. For instance, a PHN or other home visitor could regularly review the home safety situation and reinforce the risk-reduction messages by modeling the behaviors during scheduled visits.

The table below includes resources related to working with this population.

## Resources Related to FASD and Individuals with FASD

| Organization | Internet Address | Phone/E-mail |
|---|---|---|
| Bright Tomorrow FASD Support | http://fasd.brighttomorrow.com | (206) 424-4519 |
| FAS Community Resource Center | http://www.come-over.to/FAS-CRC/ | (520) 296-9172 |
| FASD Center for Excellence (part of the U.S. federal government s Substance Abuse and Mental Health Resources Administration) | http://www.fascenter.samhsa.gov | 1-866-STOPFAS (1-866-786-7327) |
| Fetal Alcohol Syndrome Consultation, Education, and Training Services, Inc. | http://www.fascets.org | wtemko@fascets.org |
| National Organization on Fetal Alcohol Syndrome | http://www.nofas.org | (202) 785-4585 or 1-800-66-NOFAS |

The *Healthy Actions for Native Babies* handout—in the folder at the back of this Workbook—is designed for use in teaching those with FASD or those with low reading abilities about safe sleep practices. You can use this handout as a starting point or as a main piece of your outreach in these populations.

## Families Who Have Experienced SIDS or Infant Death

One of the most important things to remember when working with families familiar with loss from SIDS or infant death is that *the families themselves are not to blame*. The causes of SIDS remain unknown. Even though there are ways to reduce the risk, there is no definitive way to prevent SIDS from occurring.

A SIDS death is a tragedy that often results in intense, personal grief for surviving family members and caregivers. Some parents describe the death of a child as the "most overwhelming emotional pain" they have ever experienced. The sudden, unexpected, and unexplainable nature of SIDS often adds to feelings of disbelief and shock. While going through this grief, many express doubts about their ability to get through and survive the pain; they may also question whether they will be able to find meaning in their lives again.



Although the grief experience is different for each person, families will experience some common feelings and tasks as they move through grief to eventually accept this event. These include:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Family members will move through these stages at very different rates. As family members deal with these emotions and stages, it is best to take your cues from them about how to provide support. Some parents may seem distant and cold. Others may express unpredictable and angry emotions. There is nothing you can say that will take their pain away, so it is often most helpful to listen and be present for them. Offering meals, child care, transportation, or help with other arrangements are also ways to provide support.

Grief is a physical as well as an emotional experience. It is common for family members to sleep poorly, have bad dreams, feel a stomach ache or "heart ache," or not want to be left alone in addition to their emotional ups and downs. Lack of concentration, loss of appetite, and being easily annoyed or angry at minor things or at people they are close to are also common.

Children dealing with grief have unique needs depending on their ages and their ability to understand the situation. Some may feel guilty about negative feelings they may have had about the baby. Others may worry that they will also die.

Within the context of SIDS, it is also important to realize that cultural norms may influence responses to and understanding of the death of an infant. For providers who do not share the same cultural or Tribal background as the families they are serving, it may be helpful to learn about the traditional beliefs and mourning practices among those families. You might want to talk with a local community member, Elder, or local Native health board to learn about community practices. For some families, traditional ceremonies or other traditional mourning practices may be an essential step in the grieving and healing process. For others, these traditions may be less important. The family may ask you to assist in making arrangements for these practices. Listening to and being respectful of the family's beliefs and coping strategies is critically important to avoid causing emotional harm to an already grieving family.

Keep in mind, too, that although reporting and thorough death scene investigations are critical to understanding SIDS, confidentiality is also a priority. This is especially true in small communities where many or most families are related or know each other in some way. Be respectful of people's traditions, beliefs, and privacy.

## Resources for Dealing with Grief or the Loss of a Child

- Association of SIDS and Infant Mortality Programs—at ***http://www.asip1.org/asippublications.html***
- Compassionate Friends—at ***http://www.compassionatefriends.org/Resources.aspx***
- Empty Cradle—at ***http://www.emptycradle.org/***
- Fetal and Infant Mortality Review: A Guide for Home Interviewers—at ***http://www.acog.org/from_home/departments/NFIMRHomeInterviewers02.pdf***
- Georgia Sudden Infant Death Information, Support, and Referral Project—at ***http://sidsga.org/SitePages/Support.htm***
- Massachusetts Center for SIDS—at ***http://bmc.org/pediatrics-MA-SIDS/services.htm***
- National Sudden and Unexpected Infant/Child Death and Pregnancy Loss Resource Center: Bereavement Resources—at ***http://www.sidscenter.org/bereavement/index.html***
- Northwest Infant Survival Alliance/SIDS Foundation of Washington—at ***http://www.nisa-sids.org/Bereavement.html***
- The Canadian Foundation for the Study of Infant Deaths—at ***http://www.sidscanada.org/bereave.html***

## Chapter 4:

# Strategies for Reaching Communities  Action Steps to Reduce the Risk of SIDS

### Objectives

By the end of this chapter the learner will be able to:

- Identify recognized health education approaches (including cultural competency and using Native languages).
- Describe several strategies that can be used to encourage behavior change.
- List methods for community building and organizing.
- Outline ways to network and get the message out about safe sleep for infants.
- Identify locally appropriate ways to raise awareness of SIDS in AI/AN communities.

## SIDS Impacts the Entire Community

Reducing the risk for SIDS is not just a family matter—it takes action from the whole community to understand and practice ways to reduce SIDS risk. It is essential for health educators to work with community Elders, social workers, and other outreach and health care providers to carry out planned educational programs and activities, such as those described in *Healthy Native Babies Project* Workbook. This chapter describes some strategies that you can use in your community to raise awareness about this leading cause of infant death.

Before beginning the educational efforts for this program, work with community leaders and other educators to create area-specific objectives for the region. This type of plan provides a "road map" for action, with clear guidance on how to conduct the program. Other planning considerations include:

- Setting a date and securing a location for training to take place
- Promoting the event through local newspapers, radio, TV, newsletters, posters, and billboards, and mailing invitations for the event to the intended audiences
- Preparing necessary handouts (and incentive items if available) prior to the event
- Having the necessary equipment ready for use

Finally, evaluating the effectiveness of the program by comparing the actual activities with the stated objectives is an important way to understand the impact of your efforts and to improve outcomes of future efforts.

Outreach activities can include a wide range of educational methods and techniques. For instance, the most appropriate activities for one location might be presentations to small groups of people combined with events, which rely on social marketing and communication skills to change behavior. In this case, use of instructional equipment, handouts that can be easily copied, and media involvement are vital to ensuring that the safe sleep messages "go home" with the attendees. However, this approach may not work for a neighboring community.

As you read through this chapter, consider the features and situations specific to your community or the communities in which you work. Think of ways to adapt this information to meet your audiences' needs. Be creative and flexible—no two communities are the same.

# Health Education Approaches

Educating and motivating people in your community to follow SIDS risk-reduction practices and to encourage others to follow the practices takes more than simply providing information. How directly an educational effort actually leads to desired behavior changes depends on many factors related to the context of how, when, and where the message is delivered. It includes knowledge of the source of the information and that source's credibility with those receiving information; preexisting knowledge, attitudes, and beliefs; as well as the audience's state of mind at the time the message is received.

Appendix 3 describes a few of the most recognized and effective health education approaches that educators often consider when developing strategies for health education projects. Several other considerations, essential for developing effective health education approaches for Native audiences, are outlined in this section: health literacy, cultural competence, and the use of traditional Native languages.

## Health Literacy

According to the DHHS *Healthy People 2010* report, the term *"health literacy" is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.*

Even though the practice of individuals making health decisions is timeless, the discipline of health literacy is relatively new. The concept recognizes that people may have different capacities to understand health messages, and that such understanding is heavily influenced by the communication style, skills, attitudes, biases, and expectations of the doctors, nurses, educators, and others delivering the messages. In addition, health care systems and their efficiency, social and cultural factors, and community factors also impact health literacy.

To be truly effective for all individuals—regardless of their race, ethnicity, culture, class, or age—health education must be geared to all levels of health literacy.

### Resources on Health Literacy

- Health Resources and Services Administration: ***http://www.hrsa.gov/healthliteracy***
- National Network of Libraries of Medicine: ***http://nnlm.gov/outreach/consumer/hlthlit.html***
- NIH National Library of Medicine: ***http://www.nlm.nih.gov/medlineplus/healthliteracy.html***

See **Appendix 5** for additional health literacy resources.

## Cultural Competence

Cultural competence in health care is often described as a set of behaviors, attitudes, and policies that guide a program and its staff to work effectively in cross-cultural settings by integrating culture into the program and adapting service delivery so that it reflects an understanding of cultures.

Culture includes patterns of thought, communication, language, beliefs, values, customs, rituals, expected behaviors, ways of interacting, and roles of relationships among racial, ethnic, and religious, spiritual, social, or other groups. For health care, cultural competency is most concerned with developing the capacity of the system or program to improve health and well-being by integrating the culture of the people served into the delivery of health care.

Among non-Native providers, assuring cultural competence in providing care to Native groups remains a significant challenge, not only because non-Natives may be unfamiliar with the values and priorities of that community, but also because they tend to come and go with some frequency. If local health care programs are not already attempting to provide cultural competency training to health care and social service providers new to the culture, such instruction should be included (to at least some degree) as part of the implementation of the *Healthy Native Babies Project*. Even including basic instruction, such as the *Critical Steps to Building a Positive Relationship Between Provider and Patient/Client* outlined in Chapter 3, can have a lasting impact on provider-patient interactions.

The *Healthy Native Babies Project* represents an effort to add AI/AN-specific cultural competence to recognized SIDS risk-reduction practices. Project materials and training encourage further development of community-specific cultural competence. Each outreach coordinator, health educator, and partner can choose the most appropriate outreach approach for his or her specific audience. Using the Toolkit Disk, you and your partners in this outreach can customize education materials with messages and images that are appropriate for your audience.



## Resources Related to Cultural Competence and Grief

- Promoting Cultural Diversity and Cultural Competency Self-Assessment Checklist for Personnel Providing Services and Supports to Individuals and Families Affected by SIDS and Other Infant Death—at ***http://www11.georgetown.edu/research/gucchd/nccc/documents/Checklist.SIDS-ID.pdf***
- Policy Brief: Cultural and Linguistic Competence in Family Supports—at ***http://www11.georgetown.edu/research/gucchd/nccc/documents/FamilySupports.pdf***
- Shafer, J. (1998). When an Infant Dies: Cross Cultural Expressions of Grief and Loss—at ***http://www.acog.org/departments/dept_notice.cfm?recno=10&bulletin=797***.
- Walker: Grieving in the Muskogee Creek Tribe—at ***http://www.ncbi.nlm.nih.gov/pubmed/18693381***
- Hardy-Bougere: Cultural manifestations of grief and bereavement: A clinical perspective—at ***http://www.ncbi.nlm.nih.gov/pubmed/18649443***
- Clements: Cultural perspectives of death, grief, and bereavement—at ***http://www.ncbi.nlm.nih.gov/pubmed/12875179***

For additional resources on cultural competence, see **Appendix 5**.

## Using Local Traditional Languages

There is a growing movement among AI/AN communities to reclaim traditional leadership and governance. Native academics and community leaders are stressing the need to preserve Native languages as a major component of this traditional leadership.

To honor and support the Native language revitalization movement, you may want to include Native language tools in your outreach whenever possible. Many communities include Elders who speak English as a second language, but who speak their Native language most of the time. The use of traditional languages in health materials may not only spark the interest of learners or those slightly familiar with the language, but it may also be an easy way to involve language-knowledgeable Elders in your outreach.

Existing programs and community Elders may be willing to mentor you and your colleagues in the use of the local language. Contact information for some traditional language organizations is included below.

### Resources Related to Traditional Languages

| Organization | Internet Address | Phone/E-mail |
|---|---|---|
| Alaska Native Heritage Center | http://www.alaskanative.net | (907) 330-8000 |
| Alaska Native Language Center, University of Alaska, Fairbanks | http://www.uaf.edu/anlc | (907) 474-7874 |
| Anishinaabe Language Revitalization Program | http://www.sagchip.org/language/index.asp | (989) 755-4026 |
| Bay Mills Indian Community College | http://www.bmcc.org | (800) 844-BMCC (2622) |
| Native Shop: Native American Women s Health Education Resource Center | http://www.nativeshop.org | (605) 487-7072 |
| Indigenous Governance, University of Victoria, British Columbia, Canada | http://www.web.uvic.ca/igov | (250) 721-8098 |
| Indigenous Language Institute | http://www.indigenous-language.org | (505) 820-0311 |
| National Museum of the American Indian, Smithsonian Institution | http://www.nmai.si.edu/education | NMAI-education@si.edu |
| Native Languages of the Americas: Preserving and Promoting American Indian Languages | http://www.native-languages.org | redish@native-languages.org |
| Lannan Foundation | http://www.lannan.org | (505) 986-8160 |
| Little Traverse Bay Bands of Odawa Indians | http://www.ltbbodawa-nsn.gov | (888) 309-5822 or (231) 242-1400 |

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## Resources Related to Traditional Languages (Continued)

| Organization | Internet Address | Phone/E-mail |
|---|---|---|
| Omaha Language Curriculum Development Project, University of Nebraska, Lincoln | http://omahalanguage.unl.edu/ | mawakuni-swetland2@unlnotes.unl.edu |
| Piegan Institute | http://pieganinstitute.org | (406) 338-3518 |
| Saginaw Chippewa Tribal College | http://www.sagchip.edu | (989) 775-4123 |
| Sault Tribe of Chippewa Indians | http://www.saulttribe.com | Cultural Program: (906) 632-7494 Ojibwe Language Program: (906) 632-5200 |
| Administration for Native Americans, Administration for Children and Families, DHHS | http://www.acf.hhs.gov/programs/ana/programs/Language.html | 1-877-922-9262 |
| Waadookodaading | http://www.waadookodaading.org | (715) 634-2619 |



In addition, the *Native Healthy Babies Project* Toolkit Disk allows you to incorporate Native phrases into your outreach materials. You can include one or more of the following phrases, translated in Native language, into your materials:

- Children are sacred.
- So that the People may live
- Back to sleep is traditional.
- Honor the past, learn for the future.

## The SOCO (Single Overriding Communications Objective)

One critical aspect of health outreach, no matter what specific outreach method you use, is tailoring the message to make it *accessible* to the intended audience—that is, make the message one that your audience can understand and can take to heart. The SOCO is basically your main message—it is the main thing you want to get across.

The process involves the following:

1. Develop a brief *key message*—this is your SOCO.
2. Outline three *key facts* about the topic that you want the audience to remember.
3. Identify your *target audience*—know specifically whom you want to reach with this message.
4. State your *main objective*—the one thing your audience needs to take away from your encounter.

Appendix 4 of this Workbook includes resources related to SOCO. Keep in mind that your SOCO may be slightly different depending on your audience, the type of outreach, and the location of that outreach. You may want to go through the SOCO exercise not only for the overall project, but also for planning different pieces of your project to ensure your messages stay powerful and consistent.

For more information on SOCO strategies, visit one of the following resources:

### Resources Related to SOCO

- Get your message ready for prime time: Moving from data to action—at ***http://dhs.wisconsin.gov/dph_bfch/MCH/AnnualForum/Messaging/MessageReadyforPrimeTime.pdf***
- Planning Public Health Communications—at ***http://www.uic.edu/sph/dua/Churchill/CommunicationsDUA3.htm***
- Single Overriding Communications Objective Worksheet (Part of *Forging Partnerships to Eliminate Tuberculosis Toolkit*)—at ***http://www.cdc.gov/tb/publications/guidestoolkits/forge/toolkitword.htm***
- Tools for Behavior Change Communication—at ***http://www.infoforhealth.org/inforeports/BCCtools/6.shtml***

## Grassroots Organizing and Community Outreach

Community-based models focus on the idea that empowerment begins from within. In communities of underserved people—such as poor, indigenous, disenfranchised, or immigrant communities—it is important for individuals to build an awareness of themselves within a community context. Empowering them to set their own individual and collective goals, create plans, develop programs, provide leadership, establish community norms, and celebrate victories can make a big difference in the success of your outreach and in the outcomes of the community. Communities impacted by these types of issues are best suited to address them and to create the change they envision, but they need your guidance on how to achieve such tasks.

Community organizing is a participatory process by which people organize themselves to take charge of their situation and work together for the common good. Through this process, community members move from a sense of powerlessness to powerfulness in their ability to become co-creators of public and community life. Grassroots organizing and networking are two key strategies within a broad range of community organizing methods.

Among the many activities involved in grassroots organizing and networking are the following:

- Identifying how issues impact communities though research and analysis (the *Healthy Native Babies Project* Workbook aims to assist you with this activity)
- Building a base of community supporters that will educate and mobilize other community members and allies
- Identifying the community's vision for change through a process that is controlled by the community itself
- Setting a timeline and prioritizing the goals the community develops for creating change
- Mapping out a plan that includes addressing internal and external obstacles, identifying resources needed to create the change the community desires, recruiting and mobilizing volunteers, and creating campaign messages

- Ensuring ongoing evaluation to assess what works and what doesn't work so that plans can be revised to be more effective

- Having fun and celebrating successes

The Native American Women's Dialog on Infant Mortality (NAWDIM) offers information on organizing in *Living like Neighbors: Supporting the Sovereignty and Treaty Rights of Indigenous Nations*, by L. Henry-Tanner and C. Tanner. For more information, visit either ***http://www.westernstatescenter.org/resources/tribal.html*** or ***http://www.socialjusticefund.org/news/publications***.

In addition, a number of organizations may be able to assist you with community organizing. Some resources are listed below.

## Resources Related to Community Organizing

| Organization | Internet Address | Phone |
|---|---|---|
| Center for Community Change | http://www.communitychange.org | (877) 777-1536 or (202) 339-9300 |
| Highlander Research and Education Center | http://www.highlandercenter.org | (865) 933-3443 |
| Incite! Women of Color Against Violence | http://www.incite-national.org/index.php?s=37 | (484) 932-3166 |
| Inter-Tribal Council of Michigan, Inc. | http://www.itcmi.org | (906) 632-6896 |
| National Urban Indian Family Coalition | http://www.nuifc.org | (206) 829-2229 |
| The California Partnership | http://www.california-partnership.org | (562) 862-2070 |
| Western States Center | http://www.westernstatescenter.org | (503) 228-8866 |

# Social Marketing

Social marketing, specifically within the public health realm, is often described as using culturally tailored marketing and media methods to design, implement, and manage community-focused strategies for translating health findings into education and action programs. In most cases, social marketing is most effective when it is run in collaboration with health care and/or social service systems, which provide customers with access to essential services while reinforcing educational messages.

## Countering Misconceptions

This activity is critical for any outreach that tries to change behaviors. For example, one widely held misconception is that drinking beer during pregnancy is less harmful than drinking hard liquor during pregnancy. An appropriate message should explain that beer, hard liquor, wine, and malt liquor are all different forms of alcohol, but they are all still alcohol. Follow up with the message that there is no safe level of alcohol consumption during pregnancy, no matter what form that alcohol takes.

Even though mass media (such as TV, radio, the Internet) is a critical tool for social marketing, many health-related mass-media projects have failed to show significant behavioral change. You can improve the effectiveness of your mass-media outreach using the following social marketing guidelines to craft your messages:

- Define your intended audience(s) properly.
- Create a culturally sensitive message.
- Identify and counter resistance points to your message (see the sidebar for an example of how to counter misconceptions).
- Present the message in clear, understandable language.

Many successful media plans also include the following steps:

- Select the appropriate media/venue for the audience or for the message. For example, it may be more effective to secure billboard space in the local community for your message, rather than to create TV ads to run on satellite stations.
- Strive for the proper balance of media exposure or media mix to reach the intended audience. For example, use printed flyers, posters, and postcards to reach an audience that does not spend much time on the computer.

Appendix 3 includes more information about social marketing.

Appendix 4 includes information about working with the media.

# Forging Partnerships

Your *Healthy Native Babies Project* will benefit from the knowledge, skills, and resources of other organizations and individuals. Forging partnerships is an important way to leverage or make the most of limited resources while spreading your message to a wider audience. As you plan and implement your *Healthy Native Babies Project*, consider contacting and partnering with the following types of groups.

## IHS EpiCenters and Health Boards

The IHS established 11 Tribal epidemiology centers (EpiCenters) to assist the National IHS Epidemiology Program in improving the health of AI/ANs throughout the United States. These EpiCenters provide a variety of services and assistance, including data management and reporting, emergency response, surveillance, liaison between communities and providers, training, and consultations with clinicians. The table below provides contact information for these EpiCenters in the five IHS focus Areas for this Project.

### Resources for IHS EpiCenters

| Area | Organization | Internet Address | Phone |
|---|---|---|---|
| **Aberdeen** | Northern Plains Tribal Epidemiology Center | http://www.aatchb.org/ntpec | (605) 721-1922 |
| **Alaska** | Alaska Native Health Consortium, Alaska Native Epidemiology Center | http://www.anthc.org/chs/epicenter/ | (907) 729-4567 |
| **Bemidji** | Great Lakes Inter-Tribal Council, Great Lakes EpiCenter | http://www.glitc.org/epicenter/index.html | (715)588-3324 |
| **Billings** | Montana and Wyoming Tribal Leaders Council, Rocky Mountain Tribal Epidemiology Center | http://www.rmtec.org | (406) 252-2550 |
| **Portland** | Northwest Portland Area Indian Health Board, EpiCenter | http://www.npaihb.org/epicenter | (503) 228-4185 |
| | Urban Indian Health Institute (UIHI) | http://www.uihi.org/category/maternal-child-health/ | (206) 812-3030 |

In addition, the CDC, through its Tribal Consultation Advisory Committee, partners with several Regional Health Boards to address the health and other needs of AI/ANs both on Tribal lands and outside Tribal areas. Please visit ***http://www.cdc.gov/omhd/Populations/AIAN/AIANHB.htm*** for a complete listing of the health boards and their contact information.

## Youth Involvement Organizations

There are many youth involvement projects across the country, both reservation based and urban based. In addition, a number of projects are organized by youth, for youth, to foster healing and reconnect youth to traditional AI/AN values and culture. A few of these organizations are listed below.

### Resources for Youth Organizations

| Organization | Internet Address | Phone |
|---|---|---|
| Boys and Girls Clubs in Indian Country | http://www.naclubs.org | 1-866-NACLUBS or (301) 261-6925 |
| Lummi CEDAR (**C**ommunity Health Elders, **E**ducation/**D**rug-free/**A**lcohol-free/**R**espect) Project | http://www.cedar-project.org | (360) 380-1464 |
| Sault Tribe of Chippewa Indians | http://www.saulttribe.com/ | (906) 632-7494 |



## Elder Involvement Projects

Elders are important community members with much knowledge and expertise that could benefit communities. Respectfully including Elders in programs that provide health education on SIDS risk reduction is a good way to teach communities about this important issue. Many local, regional, and national organizations work with AI/AN Elders. A comprehensive listing of Tribal entities with services for the elderly is maintained by the National Resource Center on Native American Aging at the University of North Dakota and is available at ***http://ruralhealth.und.edu/projects/nrcnaa/servicelocator.php***. Additional resources are included below.

### Resources for Elder-Serving Organizations

| Area | Organization | Internet Address | Phone |
|---|---|---|---|
| **National** | National Indian Council on Aging | http://www.nicoa.org/ | (505) 292-2001 |
| | National Resource Center on Native American Aging (NRCNAA), Center for Rural Health, University of North Dakota | http://ruralhealth.und.edu/projects/nrcnaa | (800) 896-7628 |
| **Aberdeen** | Oglala Sioux Tribe, Foster Grandparents | | (605) 867-5412 |

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## Resources for Elder-Serving Organizations (Continued)

| Area | Organization | Internet Address | Phone |
|---|---|---|---|
| **Aberdeen (Continued)** | Mandan, Hidatsa & Arikara Nation, Aging Services | http://www.mhanation.com | (701) 627-4547 |
| | Trenton Indian Service Area Senior Services | http://www.ndhealth.gov/localhd/TISA | (701) 774-0303 |
| | Flandreau Santee Sioux Tribe, Grace Moore Senior Citizens Center | http://www.fsst.org/Gracemooresenior_main.html | (605) 997-2924 |
| | Omaha Tribe of Nebraska, Senior Citizens Center | | (402) 837-5639 |
| | Sac & Fox Tribe of the Mississippi Indians in Iowa, Meskwaki Senior Service Center | http://www.meskwaki.org/Seniors.html *(Note: Must use uppercase 'S' in 'Seniors' for the link to work)* | (641) 484-3888 |
| **Alaska** | Southcentral Foundation Elders Program | http://www.southcentralfoundation.com/elder.ak | (907) 729-6500 |
| **Bemidji** | Native American Family Services (United Way of Bemidji Area) | http://unitedwaybemidji.org/ | (616) 458-4078 or (616) 457-6767 |
| **Portland** | Portland Youth and Elders Council on Poverty Reduction, Native American Youth & Family Center | http://www.nayapdx.org/community-services/portland-youth-and-elders-council.php | (503) 288-8177 |



## Maternal and Child Health Agencies and Programs

State and local maternal and child health agencies and programs help communities prevent infant mortality and focus on improving the health of mothers and children. Program activities can include improving access to prenatal and newborn care, conducting health education outreach, and supporting medical research that will improve outcomes for AI/AN families.

The Maternal and Child Health Library offers many resources through its Web site at ***http://www.mchlibrary.info/KnowledgePaths/kp_infmort.html***.

You may also want to contact the *Pregnancy Risk Assessment Monitoring System (PRAMS)* project leaders in your state. PRAMS, a surveillance project supported by the CDC and state health departments, collects state-specific population-based data on maternal attitudes and experiences before and during pregnancy and shortly after the baby is born.

Some of the information collected by PRAMS is not available from other sources. These data can assist you in identifying groups of women and infants at high risk for SIDS and other health problems, in monitoring changes in health status, and in measuring progress toward goals and objectives. You can also partner with these projects to distribute information about SIDS risk reduction in the venues where PRAMS normally collects its data. Current PRAMS contacts are listed in the table below.

## Resources for Pregnancy Risk Assessment Monitoring System (PRAMS)

| State | Contact Person | Phone | Web Address |
|---|---|---|---|
| **Alaska** | Kathy Perham-Hester | (907) 269-3447 | http://www.epi.hss.state.ak.us/mchepi/prams/default.stm |
| **Michigan** | Yasmina Bouraoui | (517) 335-9398 | http://www.cdc.gov/prams/states/michigan.htm |
| **Minnesota** | Barbara Forhnert | (651) 201-5953 | http://www.health.state.mn.us/divs/cfh/prams/ |
| **Nebraska** | Brenda Coufal | 402) 471-9044 | http://www.hhs.state.ne.us/prams |
| **Oregon** | Kenneth Rosenberg | (971) 673-0237 | http://oregon.gov/DHS/ph/pnh/prams/index.shtml |
| **South Dakota Tribal** | Jennifer Irving | (605) 721-1922 ext. 120 | http://www.cdc.gov/prams/States/SouthDakota.htm |
| **Washington** | PRAMS Coordinator | (360) 236-3497 | http://www.doh.wa.gov/cfh/PRAMS/default.htm |
| **Wisconsin** | Eleanor Cautley | (608) 267-0334 | http://dhs.wisconsin.gov/births/prams/index.htm |
| **Wyoming** | Angela Crotsenberg | (307) 777-8787 | http://www.cdc.gov/prams/states/wyoming.htm |

Note: Several Northern Tier States do not participate in PRAMS; they include: Idaho, Indiana, Iowa, Montana, and North Dakota.

### Hands-On Projects and Project Groups (Cradleboard Classes, Native Art Classes, etc.)

Organizing hands-on, culturally relevant projects creates opportunities for communities to talk about SIDS and SIDS risk reduction. These venues provide a more personal way to reach people and provide them with information and materials. These events, such as classes on making cradleboards, sessions on making other types of Native art, or classes on learning traditional Native languages, can bring people together to learn about SIDS risk-reduction strategies in their communities. You can also find ways to include Native Elders and youth in these activities.

### *Cradleboard Basics*

As discussed in earlier in this Workbook, Native Americans may have originated the concept of "back to sleep" with their longstanding historical use of the cradleboard. It is empowering for community members to remember that Native Americans have always had mechanisms for keeping babies safe.

Many AI/ANs across the United States are reclaiming the tradition of using cradleboards. Organizing and hosting a community cradleboard-making class provides a great opportunity for community members to learn a craft, creates a traditional object that is safe for babies to sleep in, and encourages discussion about issues related to safe sleep environments.

The **Native American Women's Dialog on Infant Mortality (NAWDIM) and SIDS Foundation of Washington** provide cradleboard-making classes in the Puget Sound region. For more information on the classes or on how to start a class in your area, please contact the SIDS Foundation of Washington at (206) 548-9290, or at 4649 Sunnyside Avenue, N, Suite 348, Seattle, WA 98103.

Make sure that you remind your community members not to use a cradleboard when an infant is a passenger in a car or other motor vehicle. For this situation, an infant car seat is the safest way to transport the baby and helps to ensure that he or she is protected in case of a motor vehicle crash. The National Highway Traffic Safety Administration Web site provides more information about infant car seats and safety; visit ***http://www.nhtsa.gov/Safety/CPS***.



## Sample Outreach Activities

Conducting a *Healthy Native Babies Project* provides an important opportunity for you to make a difference in your community and to help protect the well-being of infants.

The list below describes some possible activities and ideas for conducting your outreach to reduce the risk for SIDS in your community:

- Distribute educational materials at meetings of local groups (such as faith organizations), in hospital and physicians' waiting rooms, libraries, senior citizen centers, and at other locations throughout the community. Everyone needs to learn the SIDS risk-reduction strategies. Ask the staff at these locations if you can display copies of SIDS materials in a place where people can easily see them and pick them up.

- Distribute information at local community events, such as fairs, block parties, cultural celebrations, pow-wows, sports tournaments, and other observances.

- Partner with local hospitals and health centers so that they can give materials to parents and caregivers when their babies are released from the hospital, or when they come in for well-baby check ups.

- Partner with local retailers who serve Native families to distribute information on a specific day of the week, such as *Safe Sleep Saturday*.

- Organize local "town hall" meetings or community forums to discuss the myths and facts associated with SIDS among AI/AN people and to describe how individuals and organizations in the community can work together to educate others about reducing SIDS risk. Promote the event using a postcard that you create using the Toolkit Disk in this packet.

- Contact the local health department or maternal and child health organizations that have SIDS programs in your community. Ask them if they provide information on SIDS and reducing SIDS risk to new or expectant parents. If they do, encourage them to continue their efforts. If they don't, work with them to create and produce materials for their specific audiences, or give them the *Back to Sleep* campaign contact information so they can obtain their own materials and packet.

- Write letters, send e-mails, or make telephone calls to local community leaders to tell them about the importance of reaching AI/AN families with SIDS risk-reduction strategies. Encourage them to get involved in your outreach and to support efforts to spread the message within the community.



- Use a variety of materials and locations to reach out to families who have an infant younger than one year of age, anyone who is expecting a child, and everyone who may become a parent in the next few years. Let them know about your involvement in the *Healthy Native Babies Project* and explain the safe sleep messages.

- Coordinate a workshop or presentation using the training materials provided in the *Healthy Native Babies Project* Facilitator Packet (call 1-800-370-2943 to obtain your packet). You can adapt these materials for workshops or brief presentations.

- Consider contacting organizations in the community that have an interest in the safety and well-being of infants, and request a meeting with them to discuss educating their members about ways to reduce the risk of SIDS. You could even offer to work as a volunteer in return for the chance to spread safe sleep messages. Work together with agency leaders to decide how your skills and life experiences can best educate others in the AI/AN community about SIDS.

- If your community has significant radio listenership, you may want to pursue a partnership with a local station to educate listeners about SIDS. Radio is often more accessible than TV in many communities and reaches harder-to-reach audiences better than other means. Simple interviews with community leaders, public service announcements (PSAs), and paid advertisements on radio can help spread safe sleep messages to a large audience quickly and easily. Appendix 4 includes more information about working with the media, including sample scripts for short radio PSAs. Keep in mind that radio can be more effective at getting your messages to hard-to-reach audiences, including those who have difficulty reading, are homeless, or are incarcerated.

These are just a few ideas about how to get involved in educating the community about SIDS. Be creative, and remember that the most important thing is getting involved!

## Chapter 5:

# Planning and Sustaining a *Healthy Native Babies Project*

### Objectives

By the end of this chapter the learner will be able to:

- Recognize strategies for achieving community input in project development.
- Identify information sources for developing a local or regional *Healthy Native Babies: Honoring the Past, Learning for the Future Project.*
- Describe approaches for securing project funding.
- Explain project implementation, sustainability strategies, and reporting requirements.
- Understand the components and importance of a three-staged approach to evaluation.

## A True Community Effort

The majority of successful projects in AI/AN communities are the result of community-based efforts conducted by community champions and their partners. This success relies on recognizing community and partner expertise and emphasizing community input in all phases of the project. You can mobilize community partners and stakeholders at the beginning of the project to get buy-in from everyone involved. Then you and your partners can determine when and how to include groups and organizations from outside the community, based on the need for expertise not available locally. This chapter describes ways to plan a successful outreach project and put that plan into action. The chapter also outlines ways to evaluate and improve upon an outreach plan.

## Develop the Program Proposal or Plan

Regardless of its specifics, every project will benefit from a defined project plan. Plans can vary in their level of detail, but most list out specific objectives/activities and identify the persons or groups responsible for each. The plan should also include a budget reflecting the contributions of each person, agency, and partner to the overall project.

Most AI/AN populations recognize the circle as an important symbol in their cultures—the following model for program development is based on this understanding. In many communities, the Medicine Wheel represents the "seven directions"—the four directions/points of the compass (N, E, S, W), Mother Earth, the Creator, and ourselves at the center. Within this context, everything is related so that when something happens in one of the directions, the balance of the rest of the wheel is affected. The Medicine Wheel is also the circle of life—life is cyclical, and the wheel's quadrants represent the stages of life, from infancy to old age.

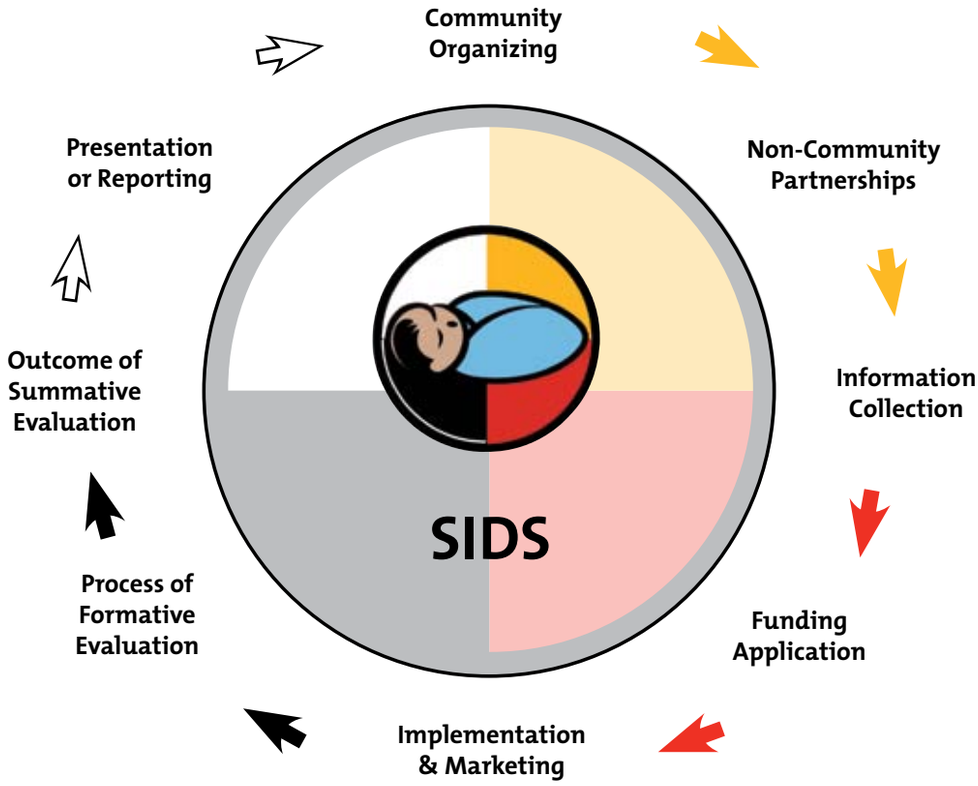
Similarly, all of the various stages of program development are related—each activity is a part of a series of activities that lead to a well thought-out plan of action, as we read the circle clockwise. For this example, place SIDS at the center because it is the focus of the program being developed (*Figure 11*).

## Sustainability Through Community-Based Program Development

To be successful, community organizing efforts need to ensure that all stakeholders are invited to the initial meetings so that their buy-in occurs from the beginning, rather than after plans have already been made. As the organizer, you should make sure that partners from outside the community have credibility, respect, and experience working with Native communities. A good rule of thumb is to make sure that marketing for community activities always includes the 5 Ws: Who, What, When, Where, and Why.

*Figure 11.*

## Sustainability Model




The following types of information may also be useful for guiding, planning, and prioritizing community needs.

- **Primary data collection** is the direct collection of data to identify gaps or disparities in health, resources, or outcomes by comparing the selected community with the state, other Tribes, or national populations. This type of data collection usually occurs in the form of surveys created from national question sets that allow comparisons once data collection is complete. By reviewing information and identifying any differences, communities can better prioritize needs and direct resources to address those needs. Generally, this information forms the basis for developing new programs, creating new facilities, and designing new services, but you can also use it to modify current projects or to address changing needs of the community.

- **Secondary data sources/analysis** refers to the use of existing reports, records, or files to collect information needed to develop a project. Reports from previously conducted studies provide statistics and recommendations that help to narrow the focus of the project and define its priorities. Reports are usually based on community data, so an existing database may be available for you to use. Another source of information—one that is often overlooked—is reviewing and analyzing medical records or service program files. You and your colleagues can use these types of resources to create your own "database" about the community. Program reports are also excellent resources for documenting history and for assessing the outreach experience of community members.

The majority of primary and secondary data sources include demographic information, such as age, gender, income, and education rates, specific to the population. This information is useful for identifying disparities and prioritizing issues for your effort. **The primary resource for this information is your local EpiCenter.** Each EpiCenter provides up-to-date information, which can be targeted to the specific populations for your intended effort. Please visit *page 54* for EpiCenter contact information.

Other methods for collecting information are described below. Each method has its own strengths and weaknesses, but each offers a significant improvement over making decisions based on undocumented needs of the community.

- The most commonly used method for collecting information is a **survey**. Surveys can provide accurate descriptions of people based either on a complete count of population or a representative sample of people from the selected community. Among the methods for collecting survey data are:
  - Self-administered questionnaires delivered/received by mail;
  - Self-administered questionnaires delivered/received at meetings or gatherings;
  - Face-to-face interviews; and
  - Telephone interviews.
- A **key informant approach** relies on people who are most likely to be knowledgeable about the community as the primary source of information. This approach usually involves a questionnaire with broad open-ended questions and a very limited number of interviews. Key informants, commonly community leaders and people in key leadership positions, are selected because they likely know both the community and its Elders and can represent the needs of the population.
- The use of **focus groups** involves gathering small groups (10 persons to 12 persons) of people to engage in a guided discussion or conversation. Presenting the group with a limited number of well thought-out and well-sequenced questions provides the focus. Focus groups can also validate data received through the needs assessment process and ensure that stakeholders have a voice in the process.
- A **community forum** allows for broad participation in a single meeting, at which all interested parties are invited to attend and participate. A community forum can usually be conducted in the same manner as a focus group, but on a larger scale.

Focus groups and community forums both provide an opportunity to learn more about other community projects and to build on or expand existing or established networks. This practice helps to reduce duplication and can make efforts more cost and time efficient. Partnering with other stakeholders also enables you to reach more people with less effort.

In terms of focus groups and community forums, consider pursuing the following stakeholders to take part in your efforts: early childhood tracking programs, maternal and child health agencies and programs, IHS offices, Tribal health departments, PRAMS centers, and any other infant- or health-related organizations.

## Funding Applications

Funding for programs or services is typically obtained through grants from private and/or public funding sources, which can include the federal government, state and local funding agencies, and private foundations. Each organization has its own format and forms for writing proposals, so following that specific format will increase your chances of getting funds. Whatever the format, there are five basic categories of information that you should be ready to provide:

**Appendix 5** includes many resources for the risk-reduction messages and other information in this Workbook. You may need to include this information in a formal proposal or plan to secure funding.

- **Need or Background Information** includes national statistics related to the topic that are then tailored to the region, state, and local community. At the community level, you may want to provide real-life examples (deleting names and any personally identifiable information) to illustrate the statistics you present.

- **Plan of Action or Intervention Information** includes innovative approaches to addressing an issue and explains your proposed solution to the problem in the form of objectives and activities. This section is also a good place to mention the person(s) responsible and evaluation criteria for each of the objectives and activities.

- The **Timeline** for the project should outline activities related to the project, from planning and pre-implementation, to project completion and post-completion evaluation. In some cases, the Plan of Action and the Timeline are combined to provide a thorough overall picture of the project.

- **Budget** should correspond to proposed objectives and activities and should include information through to the completion of the proposed project. Such information would include: personnel, fringe benefits, consultants, travel, supplies, incentives, food, telephone costs, Internet costs, copying costs, postage, and indirect costs. Indirect costs are usually provided to the fiscal manager of your grant and cover administrative costs, office space rental, gas, heat, and electricity.

- You should propose and select **Personnel** based on their abilities to do proposed tasks. Although you may have personal knowledge of their personnel's expertise, be aware that credentials are important. Include resumes for all proposed personnel in your application.

The links below provide application planning worksheets from several organizations and include examples and resources for the type of information funding agencies commonly seek in proposals. You can also use the Internet to search for other resources and examples.

### Resources Related to Funding Applications

- Center for Community Vitality: ***http://www.ag.ndsu.nodak.edu/staffres/GrantDev/checklist.htm*** (Note: Must use uppercase on "G" and "D" in "GrantDev" for link to work)
- Michael and Susan Dell Foundation: ***http://www.msdf.org/Libraries/Documents/Grant_Planning_Worksheet_2-7-2008.sflb.ashx***
- Otto Bremer Foundation: ***http://www.ottobremer.org/guidelines.php***
- The Foundation Center: ***http://www.foundationcenter.org***

## Implementation: Putting the Plan into Action

Once you secure funding for your project, you need to go back to your project plan and define what needs to happen to put the plan into action. A well-written proposal spells out what is being done (objectives), by whom (personnel), and what specific actions are being taken (activities).



### Presentation, Reporting, and Dissemination

Most funding agencies require you to submit reports and progress information throughout the funding cycle. Cycles vary, but most require reports at six and 12 months, with a final summary report due at the end of the funding period. Your funding agency may also require you to present update or overview information about your project to a board of directors or other governing body, so be sure to build the cost of these presentations into the budget for your project. At the community level, presentations may also be used to inform Tribal officials, partners, community members, and your intended audience.

Sharing your project, project plan, and project progress with others can give them ideas on how to use your experiences as models for their own efforts, to make things better for Native and non-Native communities alike.

### Sustainability

Sustainability—keeping the project up and running on schedule and on budget—requires a champion who can mobilize the community. The job requires special skills, knowledge, and experience. Some of the more common mistakes and barriers that may decrease sustainability include too little time for planning, overlap with another similar project, politics or organizational control (or lack of control), lack of trust, and lack of interest.

In addition to your overall project plan, you may want to create a sustainability plan as a step-by-step way to guide ongoing management of the project. The process of creating a

written sustainability plan can strengthen your partners' buy-in and their understanding of what is needed to keep the program operating and improving. You can also use the plan to market the program to potential financial supporters. Four areas to consider for sustaining the project include:

- Defining a vision
- Building collaboration
- Advocating for support
- Finding funding

For more information about sustainability for your project, visit the Afterschool Alliance at ***http://www.afterschoolalliance.org/documents/Toolbox/RoadtoSustainability.pdf***.

## Evaluation

Evaluation is an ongoing process used to develop, implement, and refine a project. Evaluation is an important way to determine what worked and what didn't in your *Healthy Native Babies Project*. The process of evaluation usually focuses on:

- Collecting information to assess needs;
- Analyzing and interpreting the information to help refine objectives and activities;
- Tracking activities, materials, and resources used in the project; and
- Assessing how well the project achieved the overall goal.



Several clear benefits of evaluation include:

- Increased documentation of success and failure;
- Better communication of goals and accomplishments;
- More effective acquisition of funding and community leader support; and
- Improved quality of services and achieved goals.

Although research and program evaluation have much in common, the methods needed to assess a program's effectiveness do not usually require a high level of statistical or scientific knowledge. Many of the most practical tools in evaluation require little more than simple logic and basic math skills, but be sure to use tools appropriate to the situation. One critical element for program evaluation is an objective viewpoint—that is, involving someone from outside the community or not associated or involved with the project to review outcomes without bias.

The following example illustrates a three-stage approach to evaluation.

## A Three-Stage Approach to Evaluation of a SIDS Risk-Reduction Project

### *Stage 1: Needs Assessment and Project Design*

A needs assessment identifies the problem the program is designed to address in terms of its size and features:

- How large is the problem?
- How it is distributed in the community?
- What factors are associated with or contributing to the problem?

The EpiCenters for each IHS Area offer considerable data and other resources to help you define the size of the problem and its distribution in your Area. As reported earlier, national research studies have defined many of the features that contribute to SIDS risk in Native communities.

### *Stage 2: Process Evaluation*

Process evaluation looks at how well the program was carried out or implemented. For outreach and public health staff who implement the *Healthy Native Babies Project*, process evaluation would focus on documenting the activities they completed, the types and number of resources they used, the objectives they achieved, the audience(s) they reached, and the specific educational approaches they used.

Process evaluation provides the information needed to explain the activities, materials, and approaches used in the project to those outside the project. More importantly, it associates these components with actual results or outcomes in terms of reduced SIDS rates or reduced SIDS risk after a set amount of time. Knowing these relationships is essential to identifying "best practices" and sharing these approaches with other providers and AI/AN communities.

In many cases, process evaluation contributes to broader knowledge that not only helps others, but also supports local quality improvement and improved outcomes. Efforts that were difficult or unsuccessful can provide as much useful information as those that are

successful. Seeking and using "lessons learned" is a valuable learning tool for SIDS-related efforts and other types of outreach and activities.

### *Stage 3: Outcome Evaluation*

The ultimate goal or desired outcome of the *Healthy Native Babies Project* is a reduction in SIDS rates for AI/AN communities. To achieve this end, the Project activities aim to change behaviors to reduce the known risks for SIDS. The outcome evaluation of this project, then, measures and assesses the change in:

- SIDS rates in the community over time; and
- Knowledge and or behaviors relative to SIDS risk factors in the community.

You can adopt several sources of data or information about SIDS rates (described earlier in this Workbook) to determine actual or changes in SIDS rates as part of your evaluation.

Measuring increases in the knowledge about SIDS risk factors or decreases in the actual risks (for example, more caregivers putting children to sleep on their backs) is often called an "impact measure" or "impact outcome." Even though these types of outcomes are not the actual endpoint outcomes for a *Healthy Native Babies Project*, increased use of SIDS risk-reduction strategies and knowledge about SIDS risk are key impact measures for your project. They are likely to eventually reduce SIDS rates over time.

For those working on outcome evaluation, a word of caution: Be patient. It may take several years for your *Healthy Native Babies Project* to show positive results, even when projects are well-run and effective. Literature also indicates that preventive strategies are critical, but that time is needed to actually see results.

Stay passionate about your work to improve the health of Native babies and communities, and the results will follow.

# Acknowledgements

This Workbook was developed by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) with Native American Management Services, Inc. (NAMS) under contract #HHSN275200503412C.

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The NICHD would like to thank the following individuals for their assistance in drafting and developing these materials.

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- Marilyn Pierce-Bulger, F.N.P., C.N.M., M.N., Pioneer Consulting
- Christine Rinki, M.P.H., Northern Plains Tribal Epidemiology Center

## *Healthy Native Babies Project* Workgroup

The NICHD would also like to acknowledge the members of the Workgroup who provided time, energy, and expertise to the project.

- Ralph Forquera, M.P.H., Seattle Indian Health Board
- Carole Anne Heart, Aberdeen Area Tribal Chairmen's Health Board (AATCHB)
- Diane Jeanotte, R.N., B.A.O., IHS Maternal and Child Health Program Officer
- Elizabeth Kushman, Inter-Tribal Council of Michigan, Inc.
- Allison J. La Pointe, M.P.H., Great Lakes EpiCenter
- Jacqueline Left Hand Bull, AATCHB
- Lynn Lowry, P.H.N., Winnebago Tribe of Nebraska
- Ted Mala, M.D., M.P.H., Alaska Native Medical Center, Tribal Relations and Traditional Healing, Southcentral Foundation
- Mary McClain, R.N., M.S., Massachusetts SIDS Center, Boston Medical Center, and Aberdeen Area Perinatal and Infant Mortality Review
- Kelly Murphy, Alaska Native Tribal Health Consortium
- Alice Park, M.P.H., Urban Indian Health Institute
- Leslie L. Randall, R.N., M.P.H., Nez Perce Tribal Member, University of North Carolina, and Northwest Portland Area Indian Health Board
- Christine Rinki, M.P.H., South Dakota Tribal PRAMS, Northern Plains Tribal Epidemiology Center, and Aberdeen Area Tribal Chairmen's Health Board
- Judith Thierry, D.O., M.P.H., IHS, U.S. Department of Health and Human Services

## AI/AN Families

The NICHD and the *Healthy Native Babies Project* Workgroup would like to thank the AI/AN families for their openness and assistance in depicting the daily lives of AI/ANs throughout the United States.

## Photographers

The NICHD and the *Healthy Native Babies Project* Workgroup would like to acknowledge the following photographers for their invaluable contributions to the project and materials.

- Stephen Breshear
- Dennis Brusven
- Bob Charlo
- Kraig Haver
- Al Kamuda
- Peter A. Taylor

## Language Translations

The NICHD and the *Healthy Native Babies Project* Workgroup would also like to thank the following individuals who contributed time and expertise in translating certain phrases and messages into Native languages for use in *Healthy Native Babies Project* materials.

- Oscar Alexie
- Dora Ammann, Elder
- Mark Awakuni-Swetland
- Janet Barr, Elder
- Alberta Grant Canby, Elder
- Clifford Canku
- Sean Chandler
- April Laktonen Counceller
- Nora Dauenhauer
- Richard Dauenhauer
- Moses Dirk
- Keri Edwards
- Rita Hakala
- Reverend Everett Harrison
- LeeAnn Johnson
- Favian Kennedy
- Jerome Kills Small
- Verda King
- Rory Larson
- Tim McCleary
- Vernetta Moberly
- Ethel Parker, Elder
- Tachini Pete
- Jonas Ramoth, Elder
- Connie Rivard, Elder
- Kenneth Ryan
- Emmaline Walker Sanchez, Elder
- Alberta Stephan, Elder
- Manfred J. Suina, Sr.
- Valerie Switzler
- Malcolm Wolf
- Jerry Yellowhawk

**The phrases:**

- Children are sacred.
- So That the People May Live
- Back to sleep is traditional.
- Honor the past, learn for the future.

## History of the *Healthy Native Babies Project*

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) has led the *Back to Sleep* campaign to raise awareness about ways to reduce the risk for SIDS since 1994.

Since the campaign began, the overall SIDS rate in the United States has dropped by more than 50 percent. Although the rate decline has occurred in all segments of the population, infants in certain groups, including the AI/AN communities, are still at disproportionally high risk for SIDS. AI/AN infants are nearly three times more likely to die of SIDS as white infants are. In addition, SIDS rates are particularly high in the five Northern Tier IHS Areas (Aberdeen, Alaska, Billings, Bemidji, and Portland).

To address this alarming disparity, the NICHD supports efforts to improve the effectiveness and impact of the *Back to Sleep* campaign in AI/AN communities. During 2002 and 2003, the Institute and other partners convened workgroup meetings to develop an approach for assisting local programs with SIDS risk-reduction efforts in Northern Tier Native communities.

The NICHD then assembled a smaller Workgroup, comprising stakeholders and previous workgroup members, to complete the following specific tasks:

- Develop a method for collecting qualitative data from ten sites in the five Northern Tier IHS Areas.
- Conduct focus groups with a defined primary audience in each of the five Northern Tier Areas to address risk factors for SIDS and potential approaches for reaching these audiences.
- Develop a culturally tailored implementation approach for SIDS risk reduction based on the findings of the qualitative site work in collaboration with the feedback from the Workgroup.

The NICHD and the Workgroup members used this information to develop and implement the innovative *Healthy Native Babies Project*. A team of experts—one from each of the five Northern Tier Regions—helped create this project, develop and evaluate the materials, and train outreach providers and provided technical support to those using the *Healthy Native Babies Project* materials. The NICHD consulted the Workgroup on all messages and products, including:

- *Healthy Native Babies Project* Workbook and the Toolkit Disk to assist AI/AN programs in developing community-tailored SIDS risk-reduction educational messages and materials

- Resource lists, which include programs and research related to safe sleep education and activities

- Toll-free phone number and technical assistance center (during the development phase)

- Resource stipends for 26 Tribes and organizations to develop outreach materials, including brochures, posters, printed onesies, flyers, printed bibs, postcards, and "Welcome Home" bags (filled with pamphlets, books, and other items)

- Train-the-Trainer Sessions: 10 two-day sessions, held in 2006 and 2007, to explain culturally tailored SIDS risk-reduction messages to 232 attendees, who included Tribal members, community partners, health care providers, and other stakeholders

After receiving positive feedback from the two-day training sessions and hearing about participant interest in additional training and resources, the NICHD and the Workgroup created a second-level training module/curriculum using existing materials and information. The result is the *Healthy Native Babies Project* Facilitator's Packet, which includes facilitator guides for full-day and 90-minute training sessions, presentations, other materials, and a Resources Disk. The training sessions focus on helping health care providers, community members, and others in AI/AN communities to enhance their skills and expand the reach of the *Healthy Native Babies Project*. These sessions include hands-on activities, such as working through challenge risk-reduction scenarios, engaging in message-delivery role playing, and demonstrating safe sleep environments. They also aim to build participants' confidence and overall knowledge. To order your *Healthy Native Babies Project* Facilitator's Packet, call the NICHD Information Resource Center at 1-800-370-2943 or visit ***http://www.nichd.nih.gov/sids***.

# Appendix 1: Abbreviations and Acronyms

As you read through this Workbook, you will notice many abbreviations and acronyms. These items, and their full explanations, appear below.

| | |
|---|---|
| **AAP** | American Academy of Pediatrics |
| **AI/AN** | American Indian/Alaska Native |
| **CDC** | Centers for Disease Control and Prevention |
| **CPSC** | Consumer Product Safety Commission |
| **DHHS** | U.S. Department of Health and Human Services |
| **DPT** | Diphtheria, Pertussis, and Tetanus |
| **EpiCenter** | IHS Tribal Epidemiology Center |
| **FAS** | Fetal Alcohol Syndrome |
| **FASD** | Fetal Alcohol Spectrum Disorder |
| **IHS** | Indian Health Service |
| **NICHD** | *Eunice Kennedy Shriver* National Institute of Child Health and Human Development |
| **NIH** | National Institutes of Health |
| **PHN** | Public Health Nurse |
| **PRAMS** | Pregnancy Risk Assessment Monitoring System |
| **PSA** | Public Service Announcement |
| **SIDS** | Sudden Infant Death Syndrome |
| **SUID** | Sudden Unexplained Infant Death |
| **WIC** | Special Supplemental Nutrition Program for Women, Infants, and Children |

# Appendix 2: Ways to Reduce the Risk of SIDS

Even though SIDS is not completely preventable and there is no way of knowing which babies might die from SIDS, there are some things that caregivers can do to reduce the risk of SIDS.

- **Always place the baby on his or her back to sleep for naps and at night.** The back sleep position is the safest, and every sleep time counts.

- **Place the baby to sleep on a firm sleep surface, such as on a safety-approved* crib mattress, covered by a fitted sheet.** Never place the baby to sleep on pillows, quilts, sheepskins, or other soft surfaces.

- **Keep soft objects, toys, and loose bedding out of the baby's sleep area.**

  - Don't use pillows, blankets, quilts, sheepskins, or pillow-like crib bumpers in the baby's sleep area, and keep all items away from the baby's face.

  - If you choose to use a blanket, place the baby with his or her feet at the end of the crib (sometimes called the "feet-to-foot" method). The blanket should reach no higher than the baby's chest. Tuck the ends of the blanket under the crib mattress to ensure safety.

- **Do not smoke during pregnancy and do not allow smoking around the baby.** Don't smoke before or after the birth of the baby, and don't let others smoke around the baby.

- **Do not drink alcohol during pregnancy or when breastfeeding.** Alcohol use during pregnancy is a known cause of both physical and mental problems, including permanent brain damage, developmental delays, and increased risk of SIDS. Infants can also be exposed to alcohol through breastmilk, so women who are breastfeeding should not drink alcohol.

- **Keep the baby's sleep area close to but separate from where you and others sleep.** The baby should not sleep in a bed or on a couch or armchair with adults or other children, but he or she can sleep in the same room as adults or other children. If you bring the baby into bed with you to breastfeed, put him or her back in a separate sleep area, such as a bassinet, crib, cradle, a bedside co-sleeper (an infant bed that attaches to an adult bed), or other safe sleep location when finished.

- **Think about using a clean, dry pacifier when putting the baby to bed,** but don't force the baby to take it. If it falls out while the baby is sleeping, you don't need to force it back in the baby's mouth. If breastfeeding, wait until the baby is one month old or is used to breastfeeding before trying a pacifier.

*For information on crib safety, contact the Consumer Product Safety Commission at *http://www.cpsc.gov* or at 1-800-638-2772, or talk to your health care provider.

- **Do not let the baby get overheated during sleep.** Dress the baby in light sleep clothing and keep the room at a temperature that is comfortable for an adult.

- **Avoid products that claim to reduce the risk of SIDS or to safely position the infant** because most have not been tested for effectiveness or safety. Avoid products made of foam rubber or of visco-elastic polyurethane foam (also known as Memory Foam™).

- **Do not use home monitors to reduce the risk of SIDS.** If you have questions about using monitors for other conditions, talk to your health care provider.

- **Reduce the chance that flat spots will develop on the baby's head.**
  - Provide Tummy Time when the baby is awake and someone is watching;
  - Hold the baby upright when he or she is not sleeping;
  - Change the direction that the baby lies in the crib from one week to the next (that is, baby's feet face one end of the crib for a week, then face the opposite end of the crib the next week); and
  - Avoid too much time in car seats, carriers, and bouncy seats.

- **Other things that improve infant outcomes and that may reduce SIDS risk include:**
  - Breastfeeding;
  - Getting early and regular prenatal care and preconception care; and
  - Having Public Health Nurses visit the home.

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To learn more about SIDS or to order risk-reduction education materials, contact the *Back to Sleep* campaign at:

**Phone:** 1-800-505-CRIB (2742)

**TTY:** 1-888-320-6942

**Fax:** 1-866-760-5947

**Mail:** 31 Center Drive, Building 31, Room 2A32, Bethesda, MD 20892

**E-mail:** NICHDInformationResourceCenter@mail.nih.gov
(Use subject line: BACK TO SLEEP ORDER)

**Internet:** http://www.nichd.nih.gov/SIDS

# Appendix 3: Public Health Education Approaches Selected Theories and Models

*Adapted from National Cancer Institute, NIH, DHHS. (2005). Theory at a Glance: A Guide for Health Promotion Practice, Second Edition (NIH Publication No. 05-3896). Washington, DC: Government Printing Office. Available at* ***https://cissecure.nci.nih.gov/ncipubs/detail.aspx?prodid=T052****.*

A theory is general principle that is developed to explain, organize, or predict observations about the world. A model is an illustration or diagram of the concepts in a theory. Generally, health behavior theories are principles that explain why individuals or groups behave the way they do, and explain how behaviors that may put health at risk can be changed. Communication is the act of passing information from one person to another. Communication theories explain whether the intended recipient of the information actually receives, understands, or acts upon the information that was sent.



Many of the approaches to SIDS risk reduction described in this Workbook focus on individual or family behavior change, such as smoking or infant sleep practices. Additionally, this Workbook presents approaches to communicating new concepts to individuals and communities using a variety of media. Understanding health behavior and communication theories is particularly useful because human behavior is very complex, and changing health behavior can be extremely challenging. Service providers and program planners can use this section to learn why certain strategies are or are not successful in achieving behavior change in a program, or to develop new approaches to reduce risky behavior.

## Health Belief Model (HBM)

The HBM was originally designed to explain why people did not participate in programs to prevent or detect diseases. The core components of HBM include:

- Perceived susceptibility—the subjective perception of risk of developing a particular health condition
- Perceived severity—feelings about the seriousness of the consequences of developing a specific health problem
- Perceived benefits—beliefs about the effectiveness of various actions that might reduce susceptibility and severity (taken together, perceived susceptibility and severity are labeled "threat")
- Perceived barriers—potential negative aspects of taking specific actions
- Cues to action—bodily or environmental events that trigger action

More recently, the HBM has been amended to include the notion of self-efficacy as another predictor of health behaviors, especially more complex behaviors in which lifestyle changes must be maintained over time. A wide variety of demographic, social, psychological, and structural variables may also impact people's perceptions and, indirectly, their health-related

behaviors. Some of the more important variables include educational attainment, age, gender, socioeconomic status, and prior knowledge.

### *Further Reading*

Janz, N.K., & Becker, M.H. (1984). The health belief model: A decade later. *Health Education Quarterly*, 11, 1-47.

Strecher, V.J., & Rosenstock, I.M. (1997). "The health belief model." In K. Glanz, F.M. Lewis, & B.K. Rimer (Eds.), *Health Behavior and Health Education: Theory, Research, and Practice* (Second Edition). San Francisco, CA: Jossey-Bass.



## Stages of Change

The stages of change are sometimes referred to as the transtheoretical model. The central concept of the stages of change is that individual behavior change is an ongoing process, not a single event. Individuals are at varying levels of motivation or readiness to make a change in health risk behavior. By knowing an individual's current stage, you can help set realistic program goals. You can also tailor messages, strategies, and programs to the appropriate stage.

Five distinct stages are identified in the stages-of-change construct:

- Precontemplation—Individual is not yet ready for change, often not informed or under informed about the behavior, or unsuccessfully attempted change before and is now demoralized. Individuals at this stage often avoid thinking or talking about the risk behavior.

- Contemplation—Individual is thinking about changing health risk behavior sometime in the future, but is weighing the pros and cons. Often this individual is ambivalent and may get "stuck" thinking about making change.

- Preparation—Individual is ready to make change in the very near future and has likely prepared to make change by having a plan of action and getting assistance by joining a program, buying a self-help book, or talking to a service provider.

- Action—Individual has taken concrete steps and has actually changed the identified health risk behavior. At this stage, close attention to relapse prevention is critical.

- Maintenance—Individual has sustained the behavior change and is working to avoid relapse. These individuals typically have more confidence in their ability to maintain behavior change than those in the action stage.

Individuals who are at different points in the process of change benefit from different interventions that are matched to their stage at that time. An individual who has not ever thought about making a behavior change requires a different approach than an individual who has decided to make a change. This model is particularly useful in individual interventions. By knowing an individual's current stage, providers can help set realistic goals and tailor messages, strategies, and approaches to the appropriate stage. In addition, this

process is circular: while an individual may have made a behavior change, the change may not be consistently applied or they may "regress" to an earlier stage and progress through the remaining steps again.

### *Further Reading*

Prochaska, J.O., & Velicer, W.F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, 12(1), 38-48.

## Behavioral Intentions

Studies of behavioral intentions suggest that the likelihood of adopting a desired behavior by an individual is best predicted by their intention to take that action. Intention, in turn, is influenced by their attitudes toward that behavior, their perceptions of the benefits of the behavior, and what they think their peers think about the behavior. Research by Fishbein and Ajzen supports the idea that individuals' and society's perceived attitudes are an important precursor to action. Therefore, in order to change a behavior, an individual's attitudes and perceptions of benefits must first be changed.



### *Further Reading*

Fishbein, M., & Ajzen, I. (1975). *Belief, Attitude, Intention and Behavior: An Introduction to Theory and Research*. Reading, MA: Addison-Wesley.

## Communications for Persuasion

William McGuire has described the steps an individual must be persuaded to pass through to assimilate a desired behavior. These steps are:

- Exposure to the message
- Attention to the message
- Interest in or personal relevance of the message
- Understanding of the message
- Personalizing the behavior to fit one's life
- Accepting the change
- Remembering the message and continuing to agree with it
- Being able to think of it
- Making decisions based on bringing the message to mind
- Behaving as decided
- Receiving positive reinforcement for behavior
- Accepting the behavior into one's life

These steps highlight the importance of planning a health education or social marketing campaign that considers all the factors in persuading an individual to adopt a new behavior.

This includes plans to ensure that a message is both received and absorbed. The steps draw attention to the need to stage a campaign over time in order to address the needs of the audience as they progress towards behavior change.

### *Further Reading*

McGuire, W.J. (1984). Public communication as a strategy for inducing health-promoting behavioral change. *Preventive Medicine*, 13(3), 299-313.

## Social Marketing

Social marketing has been defined as "the application of commercial marketing technologies to the analysis, planning, execution, and evaluation of programs designed to influence the voluntary behavior of target audiences in order to improve their personal welfare and that of their society" (Andreason, 1995).



This definition encompasses several key aspects of the social marketing approach; it is seen as:

- A focus on benefiting individuals and society; not a focus on profit and organizational benefits typical of commercial marketing practices
- A focus on changing behavior, not awareness or attitude change
- An approach that recognizes the target audience's primary role in the process

Social marketing practices are based on commercial marketing practices that make the consumer the central focus for planning and conducting a program. Lessons learned from social marketing stress the importance of understanding the intended audiences and designing strategies based on their wants and needs rather than what good health practice directs that they should do.

### *Further Reading*

Andreason, A. (1995). *Marketing Social Change: Changing Behavior to Promote Health, Social Development, and the Environment.* San Francisco, CA: Jossey-Bass.

Kotler, P., & Roberto, E.L. (1989). *Social Marketing: Strategies for Changing Public Behavior.* New York, NY: Free Press.

Lefebvre, R.C., & Rochlin, L. (1997). "Social marketing." In K. Glanz, F.M. Lewis, & B.K. Rimer (Eds.), *Health Behavior and Health Education: Theory, Research, and Practice* (Second Edition). San Francisco, CA: Jossey-Bass.

## Diffusion of Innovations Theory

Diffusion of innovations theory addresses how new ideas, products, and social practices spread within a society or from one society to another. The challenge of diffusion requires approaches that differ from those focused solely on individuals or small groups. It involves paying attention to the innovation (a new idea, product, practice, or technology) as well as to communication channels and social systems (networks with members, norms, and social structures).

A focus on the characteristics of innovations can improve the chances that they will be adopted and hence diffused. It also has implications for how an innovation is positioned to maximize its appeal. Some of the most important characteristics of innovations are their:

- Relative advantage—is it better than what was there before?
- Compatibility—fit with intended audience.
- Complexity—ease of use.
- Trialability—can it be tried out first?
- Observability—visibility of results.

Communication channels are another important component of diffusion of innovations theory. Diffusion theories view communication as a two-way process rather than one of merely "persuading" an intended audience to take action. The two-step flow of communication—in which opinion leaders mediate the impact of mass media—emphasizes the value of social networks (or interpersonal channels) over and above mass media for adoption decisions.

### *Further Reading*

Green, L.W., Gottlieb, N.H., & Parcel, G.S. (1987). "Diffusion theory extended and applied." In W.B. Ward (Ed.), *Advances in Health Education and Promotion.* Greenwich, CT: JAI Press.

Rogers, E.M. (1983). *Diffusion of Innovations* (Third edition). New York, NY: Free Press.

# Appendix 4: Working with the Media and the Single Overriding Communications Objective (SOCO)

The following section describes some ways to work with and contact the media, including newspapers, radio stations, Web sites, and other outlets. Think about using one or more of the following samples when conducting your *Healthy Native Babies Project* outreach. Please note that brackets [ ] surround information that you or your organization contact will need to provide.

## Sample Placement Request for Item in Newspaper/Newsletter, Magazine, etc.



Dear [Name of Copy Editor]:

**[Name of Your Organization] Spearheads Local Outreach Effort To Reduce Risk for Sudden Infant Death Syndrome (SIDS) in [Local Community Name]**

**[Name of Your Organization] recently kicked off a community education campaign to help parents and other caregivers reduce the high incidence of death from Sudden Infant Death Syndrome (SIDS) among American Indian and Alaska Native babies.**

Please review the attached document, a [Public Service Announcement, News Release, Flyer, etc.], for distribution or publication in the [Name of Publication, Newspaper, Newsletter, etc.].

I am requesting that you air or print this item from [Specific Time Period Dates, Number of Days/Weeks, etc.].

If you have any questions, you can reach me at [Contact Phone Number].

Thank you,
[Full Name of Contact]
[Title or Position]
[Name of Organization]

## Sample News/Media Release for Use in Newspaper, Newsletter, Magazine, etc.

**For Immediate Release: [DATE]**
**Contact:** [Name of Person within Your Organization Available to Answer Questions]
**Phone:** [Contact Phone Number]

**[Name of your organization] Spearheads Local Outreach Effort to Reduce Risk for Sudden Infant Death Syndrome (SIDS) in [Local Community Name]**

[Name of Your Organization] recently kicked off a community education campaign to help parents and other caregivers reduce the high incidence of death from Sudden Infant Death Syndrome (SIDS) among American Indian and Alaska Native (AI/AN) babies. Although the SIDS rate has declined in recent years, AI/AN babies are still nearly 3 times more likely to die of SIDS than white babies are.

Overall, SIDS is the leading cause of death in all infants younger than 1 year of age, and most SIDS deaths occur between the ages of 2 and 4 months. Research has shown that placing babies to sleep on their backs dramatically reduces the incidence of SIDS.

"SIDS is a community problem. We must come together to help educate the entire community about ways to reduce the risk for SIDS," said [Name of Spokesperson] of [Your Organization Name]. "This campaign is designed to bring together parents, grandparents, caregivers—everyone who is concerned about infant health—to learn how to keep our babies safe and healthy."

Activities led by [Your Organization Name] are part of the *Healthy Native Babies Project* within the national Back to Sleep campaign, led by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (part of the National Institutes of Health), the Maternal and Child Health Bureau (within the Health Resources and Services Administration), the American Academy of Pediatrics, the SIDS Alliance/First Candle, and Association of SIDS and Infant Mortality Programs.

Representatives of organizations interested in joining this community-based effort are encouraged to contact [Contact Name] at [Phone Number].

# Sample Scripts for Radio Public Service Announcements (PSAs)

## About Back Sleeping

:30-SECOND RADIO PSA

Narrator: Did you know that the safest way for babies to sleep is on their backs? This position gives the best protection against SIDS—Sudden Infant Death Syndrome—sometimes called "crib death." American Indian and Alaska Native babies are 2 to 4 times more likely to die of SIDS than other American babies. Protect our future generations! Remember, babies sleep safest on their backs. To learn more about SIDS, call 1-800-505-CRIB. That's 1-800-505-2742. A public service of this station and the [Your Organization Name].

## About Dressing Babies for Sleep

:15-SECOND RADIO PSA

Narrator: Dress babies in light sleep clothes to reduce the risk for SIDS—Sudden Infant Death Syndrome. Protect our future generations! To learn more about SIDS, call 1-800-505-CRIB. A public service of this station and the [Your Organization Name].

## About Preventing Baby from Getting Overheated (Very Important in Winter Months)

:30-SECOND RADIO PSA

Narrator: As you bundle up this winter, remember that you can reduce the chance your baby will die of SIDS—Sudden Infant Death Syndrome—by dressing your baby in light sleep clothes and keeping the room at a temperature comfortable for an adult. Your baby is too warm if you notice sweating, flushed cheeks, heat rash, or rapid breathing. Protect our future generations! To learn more about SIDS, call 1-800-505-CRIB. That's 1-800-505-2742. A public service of this station and the [Your Organization Name].

## About Drinking During Pregnancy or While Breastfeeding

:30-SECOND RADIO PSA

Narrator: Remember that drinking alcohol when pregnant or breastfeeding can harm babies and increases the risk for SIDS—Sudden Infant Death Syndrome. If you are pregnant or breastfeeding, keep your baby safe by not drinking alcohol. Protect our future generations! To learn more about SIDS, call 1-800-505-CRIB. That's 1-800-505-2742. A public service of this station and the [Your Organization Name].

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## About SIDS Awareness

:15-SECOND RADIO PSA

Narrator: Help protect babies in [Community Name] from Sudden Infant Death Syndrome—SIDS—sometimes called "crib death." Always place babies to sleep on their backs, for naps and at night. Protect our future generations! To learn more about SIDS, call 1-800-505-CRIB. A public service of this station and the [Your Organization Name].

---

## About Smoking Commercial Tobacco

:15-SECOND RADIO PSA

Narrator: Help reduce the risk for SIDS—Sudden Infant Death Syndrome—by not smoking during pregnancy or around your baby. Don't let others smoke around your baby, anywhere in the house or in the car. Protect our future generations! To learn more about SIDS, call 1-800-505-CRIB. A public service of this station and the [Your Organization Name].

---

## About Smoking Commercial Tobacco

:30-SECOND RADIO PSA

Narrator: Smoking during pregnancy can cause long-term health problems and increases the chance that your baby will die of SIDS—Sudden Infant Death Syndrome. Give your baby a smoke-free environment before and after birth. Don't smoke while you are pregnant. And don't smoke or allow others to smoke around your baby, anywhere in the house, or in the car. Protect our future generations! To learn more about SIDS, call 1-800-505-CRIB. A public service of this station and the [Your Organization Name].

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# Single Overriding Communications Objective (SOCO) Work Sheet*

## Key Message:

In one brief paragraph, please state the key point or objective in doing the interview. This statement should reflect what you would like to see as the lead paragraph in a newspaper story or broadcast news report.

## Key Facts:

What are the three facts or statistics you would like the public to remember as a result of reading or hearing about this story?

1.

2.

3.



## Target Audience:

Who is the main audience or population segment you would like this message to reach?

*Primary:*

*Secondary:*

## Interview Objective:

What is the one message the audience needs to take away from this report/interview?

## Primary Media Contact:

Who in your office/organization will serve as the primary point of contact for the media?

*Name:*

*Phone:*

*Date and time available:*

*Developed by Robert J. Howard, former assistant to the director, National Center for Infectious Diseases, CDC

# Appendix 5: Information Sources

This appendix includes source information for most of the scientific and evidence-based references that support the information provided in this Workbook. It is not intended to be an exhaustive list of references/resources related to SIDS or other topics, but is intended as a starting point for individuals' own research.

General Information about SIDS, SIDS Risk Factors, and Health ..... **92**

Pregnancy-Related Factors ..... **93**

Overheating ..... **93**

Maternal Alcohol Use ..... **94**

Commercial Tobacco Use ..... **95**

Safe Sleep Environments, Sleep Locations, and Sleep Surfaces ..... **95**

Breastfeeding ..... **96**

Pacifiers ..... **97**

Public Health Nurse (PHN) Visits ..... **98**

Bed Sharing/Co-Sleeping ..... **98**

Strategies for Reaching Communities ..... **99**

Action Steps to Reduce SIDS Risk in Communities ..... **100**

Planning and Sustaining a *Healthy Native Babies Project* ..... **101**

## General Information about SIDS, SIDS Risk Factors, and Health

- *Eunice Kennedy Shriver* National Institute of Child Health Development (NICHD), part of the National Institutes of Health (NIH) within the U.S. Department of Health and Human Services (DHHS), provides overall leadership and maintenance of the national *Back to Sleep* campaign. For more information, visit the NICHD Web site at:
  - *Back to Sleep* Web site: ***http://www.nichd.nih.gov/sids/***
  - *Back to Sleep* publications and materials: ***http://www.nichd.nih.gov/publications/pubskey.cfm?from=sids***
  - A to Z Health and Human Development Topic—Sudden Infant Death Syndrome (SIDS): ***http://www.nichd.nih.gov/health/topics/Sudden_Infant_Death_Syndrome.cfm***
  - A to Z Health and Human Development Topic—Tummy Time: ***http://www.nichd.nih.gov/health/topics/Tummy_Time.cfm***
  - NICHD News Releases about SIDS: ***http://www.nichd.nih.gov/news/releases/news.cfm***, select keyword "Sudden Infant Death Syndrome (SIDS)" and year "All"
- American Academy of Pediatrics (AAP) Web site has numerous articles on SIDS research and policy statements. AAP Web site: ***http://www.aap.org***
  - AAP Task Force on Reducing Sudden Infant Death Syndrome. (2005). The changing concept of Sudden Infant Death Syndrome: Diagnostic coding shifts, controversies regarding the sleep environment, and new variable to consider in reducing risk. *Pediatrics, Nov;116*(5), 1245-1255. Available through the AAP Web site at ***http://pediatrics.aappublications.org/cgi/content/full/116/5/1245***.
- The Centers for Disease Control and Prevention (CDC) provides information about SIDS, Sudden Unexplained Infant Death (SUID), and related topics at ***http://www.cdc.gov/SIDS/index.htm***.
- First Candle/SIDS Alliance Web site provides access to research studies for parents and professionals on current trends and advancements in the area of SIDS: ***http://www.sidsalliance.org***.
- Health Resources and Services Administration, also a sponsor of the *Back to Sleep* campaign, supports the National Sudden and Unexplained Infant/Child Death and Pregnancy Loss Resource Center; visit ***http://www.sidscenter.org*** for more information.
- Indian Health Service (IHS) has numerous documents on SIDS reduction and prevention; visit ***http://www.ihs.gov/*** and search for "SIDS" in the "Search IHS.gov" area.
- National Indian Health Board advocates on behalf of all Tribal governments and AI/ANs in their efforts to provide quality health care; the Board, in partnership with the CJ Foundation and the DHHS, distributes *Face Up to Wake Up*™; visit ***http://www.nihb.org/docs/res_kit_aian_sids.pdf*** for more information.

- National Sudden and Unexplained Infant/Child Death and Pregnancy Loss Resource Center: ***http://www.sidscenter.org***

- Paterson, D.S., Trachtenberg, F.L., Thompson, E.G., Belliveau, R.A., Beggs, A.H., Darnall, R., Chadwick, A.E., Krous, H.F., & Kinney, H.C. (2006). Multiple serotonergic brainstem abnormalities in sudden infant death syndrome. *Journal of the American Medical Association, Nov1*;296(17), 2124-2132. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/17077377***.

- SIDS Resources has a Web site that includes a variety of resources for new parents: ***http://www.sidsresources.org/newparents/parentsabout.shtml***.

- Thach, B. (2008). Tragic and sudden death: Potential and proven mechanisms causing sudden infant death syndrome. *European Molecular Biology Organization (EMBO) Reports*, *9*(2), 114-118. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/18246101***.

- U.S. National Center for Health Statistics (NCHS) provides U.S. health statistics on numerous topics, including infant mortality and SIDS; visit ***http://www.cdc.gov/nchs/fastats/infant_health.htm*** for more information.

- Urban Indian Health Institute (UIHI), established in July 2000 as a division with the Seattle Indian Health Board, is a community health center focusing on urban AI/ANs. The UIHI provides centralized nationwide management of health surveillance, research, and policy considerations regarding the health status disparities affecting AI/ANs; visit ***http://www.uihi.org/*** for more information.

## Pregnancy-Related Factors

- Alexander, G.R., & Kotelchuck, M. (2001). Assessing the role and effectiveness of prenatal care: History, challenges, and directions for the future. *Public Health Reports, Jul-Aug;116*(4), 306-316. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/12037259***.

- NICHD A to Z Health and Human Development Topic—Pregnancy: ***http://www.nichd.nih.gov/health/topics/pregnancy.cfm***

## Overheating

- Iyasu, S., Randall, L.L., Welty, T.K., Hsia, J., Kinney, H.C., Mandell, F., McClain, M., Randall, B., Habbe, D., Wilson, H., & Willinger, M. (2002). Risk factors for sudden infant death syndrome among Northern Plains Indians. *Journal of the American Medical Association, Dec4;288*(21), 2717-2723. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/12460095***.

- NICHD, NIH, DHHS. (2006). *Safe Sleep for Your Baby: What does a safe sleep environment look like?* Available at ***http://www.nichd.nih.gov/publications/pubs/upload/Safe_Sleep_2009_Eng.pdf***.

- Randall, L.L., Welty, T.K., Willinger, M., Iyasu, S.I., & the Aberdeen Area Infant Mortality Study Steering Committee. *Mi in a kin towani ewaktonji kte ni, I will never forget my child.* A report prepared for the Aberdeen Area Chairman's Health Board. June 30, 1998.


## Maternal Alcohol Use


- Randall, L.L., Welty, T.K., Willinger, M., Iyasu, S.I., & the Aberdeen Area Infant Mortality Study Steering Committee. *Mi in a kin towani ewaktonji kte ni, I will never forget my child.* A report prepared for the Aberdeen Area Chairman's Health Board. June 30, 1998.

- Evanson, D., & Matthews, D., for the Office of Fetal Alcohol Syndrome, State of Alaska. (1998). *The Developing Baby.* Retrieved from ***http://www.hss.state.ak.us/fas/info/developingBaby.htm***.

- Iyasu, S., Randall, L.L., Welty, T.K., Hsia, J., Kinney, H.C., Mandell, F., McClain, M., Randall, B., Habbe, D., Wilson, H., & Willinger, M. (2002). Risk factors for sudden infant death syndrome among Northern Plains Indians. *Journal of the American Medical Association, Dec4;288*(21), 2717-2723. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/12460095***.

- La Leche League International. (2008). *What about drinking alcohol and breastfeeding?* Retrieved from ***http://www.lalecheleague.org/FAQ/alcohol.html***.

- Office of Fetal Alcohol Syndrome, State of Alaska. (2002). *Do Children Outgrow FASD?* Retrieved from ***http://www.hss.state.ak.us/fas/info/faqs_outgrowFAS.htm***.

- Randall, L.L., Krogh, C., Welty, T.K., Iyasu, S.I., & Willinger, M. (2001). The Aberdeen Indian Health Service infant mortality study: Design, methodology, and implementation. *American Indian Alaska Native Mental Health Research: A Journal of the National Center, 10*(1),1-20. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/11484150***.

- Riley, E.P., & McGee, C.L. (2005). Fetal Alcohol Spectrum Disorders: An overview with emphasis on changes in brain and behavior. *Experimental Biology and Medicine (Maywood), Jun;230*(6), 357-365. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/15956765***.

- Schulte, P. (1995). Minimizing alcohol exposure of the breastfeeding infant. *Journal of Human Lactation, Dec;11*(4), 317-319. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/8634109***.

- Wattendorf, D.J., & Muenke, M. (2005). Fetal Alcohol Spectrum Disorders. *American Family Physician, 72*, 279-282, 285; retrieved from ***http://www.aafp.org/afp/20050715/279.html***.

## Commercial Tobacco Use


- Anderson, M.A., Johnson, D.C., & Batal, H.A. (2005). Sudden infant death syndrome and prenatal maternal smoking: Rising attributed risk in the Back to Sleep era. *BMC Medicine, Jan;3*, 4. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/15644131***.

- CDC, DHHS. (2006). *Babies whose mothers smoke before and after birth are three to four times more likely to die from SIDS.* Retrieved from ***http://www.cdc.gov/tobacco/sgr/sgr_2004/consumerpiece/page5.htm***.

- *Health Effects of Second Hand Smoke Exposure: Childhood Illnesses & Diseases*, Ontario Campaign for Action on Tobacco; retrieved from ***http://www.ocat.org/healtheffects/childhood.html***.

- Project Cork aims to assemble and disseminate current, authoritative information on substance use and abuse for clinicians, health care providers, human service personnel, and policy makers. For more information, visit ***http://www.projectcork.org***.

  - *Maternal smoking during pregnancy remains the most important modifiable risk factor for SIDS*; retrieved from ***http://www.projectcork.org/bibliographies/data/Bibliography_Pregnancy.html***.

- American Lung Association; retrieved from Healthy Air, at ***http://www.lungusa.org/healthy-air***.

- *Stop Smoking, Stop SIDS*; retrieved from ***http://www.sidsma.org/professionals/StopSmoking.html***.

- Wisborg, K., Kesmodel, U., Henriksen, T.B., Olsen, S.F., & Secher, N.J. (2000). A prospective study of smoking during pregnancy and SIDS. *Archives of Disease in Childhood, Sep;83*, 203-206. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/10952633***.


## Safe Sleep Environments, Sleep Locations, and Sleep Surfaces


- AAP Task Force on Reducing Sudden Infant Death Syndrome. (2005). The changing concept of Sudden Infant Death Syndrome: Diagnostic coding shifts, controversies regarding the sleep environment, and new variable to consider in reducing risk. *Pediatrics, Nov;116*(5), 1245-1255. Available through the AAP Web site at ***http://pediatrics.aappublications.org/cgi/content/full/116/5/1245***.

- Healthy Child Care America, SIDS Information; available at ***http://www.healthychildcare.org/sids.html.***

- Moon, R.Y., Kotch, L., & Aird, L. (2006). State child care regulations regarding infant sleep environment since the Healthy Child Care America-Back to Sleep Campaign. *Pediatrics, Jul;118*(1), 73-83. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/16818551***.

- Morgan, K.H., Groer, M.W., & Smith, L.J. (2006). The controversy about what constitutes safe and nurturant infant sleep environments. *Journal of Obstetric, Gynecological, and Neonatal Nursing, Nov-Dec;35*(6), 684-691. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/17105632***.

- NICHD, NIH, DHHS. (2006). *Safe Sleep for Your Baby: What does a safe sleep environment look like?* Available at ***http://www.nichd.nih.gov/publications/pubs/upload/Safe_Sleep_2009_Eng.pdf***.

- Paluszynska, D.A., Harris, K.A., & Thach, B.T. (2004). Influence of sleep position experience on ability of prone-sleeping infants to escape from asphyxiating microenvironments by changing head position. *Pediatrics, Dec;114*(6), 1634-1639. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/15574627***.

- Thach, B.T., Rutherford, G.W. Jr., & Harris, K. (2007). Deaths and injuries attributed to infant crib bumper pads. *Journal of Pediatrics, Sep;151*(3), 271-274, 274.e1-3. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/17719936***.


## Breastfeeding


- Alm, B., Wennergren, G., Norvenius, S.G., Skjaerven, R., Lagercrantz, H., Helweg-Larsen, K., Irgens, L.M. (2002). Breastfeeding and the sudden infant death syndrome in Scandinavia, 1992-95. *Archives of Diseases in Childhood, Jun;86*(6), 400-402. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/12023166***.

- American Academy of Breastfeeding Medicine is a worldwide organization of physicians dedicated to the promotion, protection, and support of breastfeeding and human lactation. The Academy recognizes the benefits of breastfeeding at ***http://www.bfmed.org/media/files/documents/pdf/press releases/strong evidence base for benefits of breastfeeding (3-19-09).pdf*** and through its Web site at ***http://www.bfmed.org***.

- Chen, A., & Rogan, W.J. (2004) Breastfeeding and the risk of post-neonatal death in the United States. *Pediatrics, May;113*(5), e435-e439. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/15121986***.

- La Leche League International: *Resources*: ***http://www.llli.org/resources.html***

- McVea, K.L., Turner, P.D., & Peppler, D.K. (2000). The role of breastfeeding in sudden infant death syndrome. *Journal of Human Lactation, Feb;16*(1), 13-20. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/11138219***.

- Mosko, S., Richard, C., & McKenna, J. (1997). Infant arousals during mother-infant bed sharing: Implications for infant sleep and sudden infant death syndrome research. *Pediatrics, Nov;100*(5), 841-849. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/9346985***.

- NICHD A to Z Health and Human Development Topic—Breastfeeding: ***http://www.nichd.nih.gov/health/topics/Breastfeeding.cfm***

- The AAP provides numerous resources and information related to breastfeeding at ***http://www.aap.org/healthtopics/breastfeeding.cfm***, including the *AAP Policy on Breastfeeding and the Use of Human Milk*, at ***http://www.aap.org/breastfeeding/PolicyOnBreastfeedingAndUseOfHumanMilk.html***.

- The Office of Women's Health, DHHS, maintains a Web site about breastfeeding at ***http://www.4woman.gov/breastfeeding/index.cfm?page=227***.

## Pacifiers

- American Academy on Pediatric Dentistry (AAPD) is a national membership organization representing the specialty of pediatric dentistry and including more than 7,000 pediatric dentists. Web site: ***http://www.aapd.org***.

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## Strategies for Reaching Communities

- Bereavement resources: Please see the Resources for *Dealing with Grief or the Loss of a Child* information on page 44 of this Workbook.


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- National Cancer Institute, NIH, DHHS. (2004). Making Health Communications Programs Work: A Planner's Guide (NIH Publication No. 04-5145). Washington, DC: Government Printing Office. Available at ***https://cissecure.nci.nih.gov/ncipubs/detail.aspx?prodid=T068***.

- Pierce-Bulger, M., & Nighswander, T. (2001). Nutaqsiivik: An approach to reducing infant mortality using quality improvement principles. *Quality Management in Health Care, Spring;9*(3), 40-46. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/11372502***.

- State of Alaska, Behavioral Health, Office of Fetal Alcohol Syndrome: ***http://www.hss.state.ak.us/fas/***

- Wattendorf, D.J., & Muenke, M. (2005). Fetal Alcohol Spectrum Disorders. *American Family Physician, 72*, 279-282, 285; retrieved from ***http://www.aafp.org/afp/20050715/279.html***.




## Action Steps to Reduce SIDS Risk in Communities


- Prochaska, J.O., DiClemente, C.C., & Norcross, J.C. (1992). In search of how people change: Applications to addictive behaviors. *American Psychologist, 47*(9), 1102-1114. Abstract available at ***http://www.ncbi.nlm.nih.gov/pubmed/1329589***.

- Institute of Medicine, within the National Academy of Sciences, offers information health literacy through its Web site at ***http://www.iom.edu/Activities/PublicHealth/HealthLiteracy.aspx***.

- Motivational Interviewing, part of the National Registry of Evidence-Based Programs and Practices, ***http://www.motivationalinterview.org/***

- National Center for Cultural Competence at Georgetown University has an entire portfolio of information on cultural competence at ***http://www11.georgetown.edu/research/gucchd/nccc/***.

- Turning Point, a former initiative of the Robert Wood Johnson Foundation and the W.K. Kellogg Foundation, sought to transform and strengthen the public health system in the United States by making it more community-based and collaborative. Information on social marketing and public health that resulted from this initiative is available at ***http://www.turningpointprogram.org/Pages/socialmkt.html***.

## Planning and Sustaining a *Healthy Native Babies Project*

- Catalog of Federal Domestic Assistance (CFDA) is a database of all federal programs available to state and local governments; federally recognized Indian Tribal governments; territories (and possessions) of the United States; domestic public, quasi-public, and private for-profit and non-profit organizations and institutions; specialized groups; and individuals. Visit the CFDA Web site at ***http://www.cfda.gov/***.

- Pew Charitable Trusts is a non-profit organization that aims to: improve public policy by studying and promoting policy solutions for various domestic and international problems; inform the public through impartial, fact-based polling and other research-based tools; and stimulate civic life by encouraging and supporting organizations and institutions that enhance well-being. For more information, visit the Pew Web site at ***http://www.pewtrusts.org/***.

- Robert Wood Johnson Foundation supports and conducts efforts to improve the health and health care of all Americans. The Foundation's goal is to help Americans lead healthier lives and get the care they need. The Foundation also provides grant support to eligible organizations. For more information, visit the Foundation Web site at ***http://www.rwjf.org/***.

- W.K. Kellogg Foundation aims to help create conditions in communities for children and families to be successful by helping children to learn, develop, and stay healthy, and by strengthening families within the context of communities and places. The Foundation provides investments in and grant support for eligible organizations. For more information, visit the Foundation Web site at ***http://www.wkkf.org/***.



In addition to the resources listed above, the following resources, provided in Chapter 5, are also useful for sustaining an outreach project:

- Afterschool Alliance: *Road to Sustainability*
  ***http://www.afterschoolalliance.org/documents/Toolbox/RoadtoSustainability.pdf***

- Center for Community Vitality
  ***http://www.ag.ndsu.nodak.edu/staffres/GrantDev/checklist.htm***
  (Note: Must use uppercase on "G" and "D" in "GrantDev" for link to work)

- Michael and Susan Dell Foundation
  ***http://www.msdf.org/Libraries/Documents/Grant_Planning_Worksheet_2-7-2008.sflb.ashx***

- Otto Bremer Foundation
  ***http://www.ottobremer.org/guidelines.php***

- The Foundation Center
  ***http://www.foundationcenter.org***

## How can I protect my baby in my home?

- Don't smoke around the baby.
- Don't let others smoke around the baby.

- Don't drink alcohol when caring for your baby or when breastfeeding the baby.

- Have a Public Health Nurse visit your home.

## What else can I do to help my baby?

- Reduce the chance that flat spots will develop on the baby's head.
  - Provide Tummy Time when the baby is awake and someone is watching.
  - Hold the baby upright when he or she is not sleeping.
  - Change the direction that the baby faces in the crib from one week to the next (that is, baby's feet face one end of the crib for a week, then face the opposite end of the crib the next week).
  - Avoid too much time in car seats, carriers, and bouncy seats.

*Crib Head*

*Crib Head*

- Breastfeed your baby.
- Take your baby to health care appointments (sometimes called "well baby checkups") on a regular basis, as recommended.

# *Healthy Actions for Native Babies*

Use this handout to help educate those within American Indian/Alaska Native communities who might have cognitive problems, such as Fetal Alcohol Syndrome (FAS), Fetal Alcohol Spectrum Disorder (FASD), and traumatic brain injury, or who might not read well.

The risk-reduction actions described here mirror those provided in Appendix 2 of the *Healthy Native Babies Project* Workbook.

## How can I protect my baby before it is born?

- Don't smoke during your pregnancy.

- Don't drink while you are pregnant or breastfeeding.

- Get early and regular prenatal care.

- Have a Public Health Nurse visit your home.

## How should my baby sleep?

- Place baby on its back to sleep for every sleep time, for naps and at night.

*Basket*

*Box or Carton*

*Drawer*

*Wash Tub*

- Place baby on a firm surface for sleeping, such as a safety-approved crib or alternative sleep surface, such as a basket, box or carton, drawer, or wash tub.
- Don't leave soft things, blankets, toys, pillows, padded bumpers, or quilts in the baby's sleep area.
- Keep all items away from baby's face.

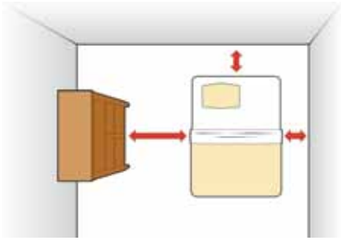
- Don't let baby get too warm during sleep.
- Dress baby in light sleep clothing, such as a sleeper (sleep suit with sleeves and feet "built in") or onesie (one piece sleep suit).
- Don't use a blanket.
- Keep the temperature comfortable for you and it will also be fine for baby.

- Give the baby a pacifier to suck on while he or she is falling asleep.
  - Don't force the baby to take the pacifier.
  - It is OK if the pacifier falls out while the baby is sleeping—You don't need to put it back in baby's mouth.
  - Wait until baby is used to breastfeeding before using a pacifier.

## Where should my baby sleep?

- Make a separate place for your baby to sleep that is close to you and in the same room. This is the safest place for baby to sleep.

- Don't sleep with baby on a couch, armchair, sofa, or waterbed. The baby could suffocate if it gets trapped in these surfaces or between your body and the surfaces.

- Don't let siblings, pets, or other children sleep in bed with the baby. The baby could suffocate if a person or animal rolls over on top of it.

- Place baby in area of bed where an adult isn't sleeping, or in the area just above where adult head is.
- Keep baby away from adult bedding.
- Move bed away from walls and other furniture so baby can't fall and get trapped between the bed and another surface.
- Place mattress low to or on the floor, away from walls, so the baby can't fall or get trapped between the bed and the wall.