



ISSUE BRIEF

Data-Driven Decisions: Using Surveillance Data to Inform Infant Safe Sleep Programs

Since the introduction in 1992 of the American Academy of Pediatrics (AAP) recommendation to place infants to sleep on their backs and the initiation of the National Institute of Child Health & Human Development's *Back to Sleep Campaign* in 1994, there has been a significant decrease in the number infant deaths attributed to Sudden Infant Death Syndrome (SIDS). SIDS is one cause of infant deaths that falls within a broad category of Sudden Unexpected Infant Deaths (SUID), which also includes suffocation, asphyxia and entrapment.

In recent years, the decrease in deaths attributed to SIDS has plateaued while deaths from other causes of SUID that occur during sleep have increased. Because established risk factors for SIDS are strikingly similar to those for sleep-related deaths, community prevention activities focus on parental and infant-caretaker behaviors related to the infant sleep environment. The October 2011 AAP policy release, "SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommendations for a Safe Infant Sleeping Environment", strengthens the importance of the infant sleep environment while emphasizing breastfeeding as an additional protective measure.

Because of the growing emphasis on evidence-based practices and data-driven grant program deliverables, there is an increased need for Epidemiologists to participate in the planning of state public health programs, particularly in state maternal and child health programs. Surveillance data, such as that collected through the Pregnancy Risk Assessment Monitoring System (PRAMS), can guide decision making for programs, especially those related to infant sleep. PRAMS is conducted in 40 states and New York City and uses standardized data-collection methods, allowing data to be compared among sites. The questionnaire consists of a core component used by all participating states and a state-specific component developed to address the particular data needs of each state. Below are topics in the PRAMS questionnaire that can be used to assess infant safe sleep programs.

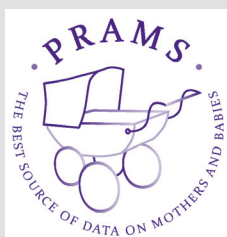
- Infant sleep position
- Smoke exposure
- Breastfeeding
- Pregnancy intention
- Prenatal care
- Interconceptional care
- Depression
- Medicaid and WIC participation
- Physical abuse
- Insurance coverage
- Infant health and care
- Bed sharing
- Sleep environment
- Provider/other advice on infant sleep behaviors
- Cigarette smoking and alcohol use

Using data such as PRAMS, Epidemiologists working with state maternal and child health programs can bridge the gap between the collection and analysis of data and the use of that data to inform programmatic work and change policies related to safe sleep practices. Specific ways in which Epidemiologists can be beneficial to program and policy planning include determining the generalizability of particular data results, identifying appropriate comparison groups for high risk populations, assessing the validity of comparing more than one data source and assisting in the development of outcome measures for evaluation of interventions during the planning phase. The purpose of this issue brief is to showcase state-specific examples and use of PRAMS in informing programmatic change.

Examples From the Field: PRAMS Data Supporting Infant Safe Sleep Work

ALASKA

Public Health Concern: Infant mortality review data indicated that 43 percent of Alaskan infant sleep-related deaths occurred while the infant was sharing a sleep surface. Almost all (99 percent) of the deaths had other known risk factors for infant mortality, such as maternal tobacco use or sleeping with an impaired caregiver, indicating that bed sharing was not an independent risk factor for infant mortality.



Action

- To obtain additional information on these risk factors among all live births, Alaska PRAMS data from 2000-2008 were examined and indicated that tobacco use during pregnancy had not changed in recent years and around 15 percent of mothers reported tobacco use. Only 76 percent of new mothers in 2008 most often placed their infant to sleep on his or her back. Frequent bed sharing increased since 2000, and in 2008 only 17 percent of mothers said their baby never shares a bed with someone else while almost 50 percent said their baby always or often shares a bed.
- Data from mothers reporting frequent bed sharing (always or often) were examined for other behaviors that increased their infants' risk of postneonatal mortality. Forty percent of the mothers who reported frequent bed sharing on PRAMS reported substance use, smoking, high levels of alcohol use or most often placing their infant to sleep on their stomach. PRAMS comment data provided qualitative information on mothers' reasons related to infant sleep position, use of commercial products, and when, how, and why they bed share.
- After examining the infant mortality review data on deaths, the PRAMS data on all infants, and the PRAMS comment data, it was concluded that bed sharing is not a simple concept or behavior and more than one risk factor is often involved. Because of PRAMS, Alaska now has a targeted prevention campaign for those identified most at risk.

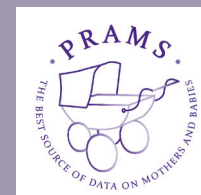
Impact

- PRAMS data were used to develop and guide the Alaska Safe Sleep Initiative to prevent sleep-related infant deaths. A statewide health facility assessment identified the need for policy and education materials, and model practices.
- The Alaska Infant Safe Sleep Task Force of diverse stakeholders was convened and an Infant Safe Sleep Summit was held in 2010.
- PRAMS data was used to support a grant proposal to develop and test messages, materials and strategies for changing parental behavior regarding infant sleep practices.
- A social marketing plan was created and focus groups were conducted to better understand knowledge, attitudes and behaviors related to infant sleep among Alaskan parents. Pamphlets, posters, a public service announcement radio script and website marketing will be produced based on the research and focus-group findings.

Building Capacity & Providing Data

In ongoing efforts to support state and local maternal and child health programs, the Association of SIDS and Infant Mortality Programs (ASIP) and the Association of Maternal & Child Health Programs (AMCHP) co-sponsor a series of quarterly webinars to strengthen SUID, SIDS, Infant Safe Sleep and bereavement services provided across the United States. A June 2011 webinar focused on states use of PRAMS data to inform SUID/SIDS/safe sleep programs and policy development.

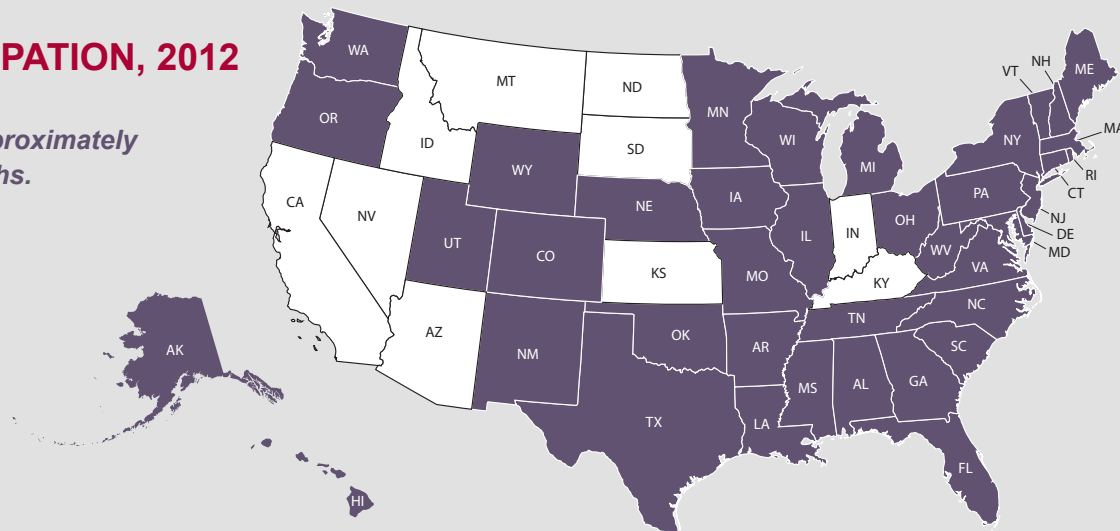
- **AMCHP** represents state public health leaders promoting the health of America's families through support for state maternal and child health programs, including services for children and youth with special health care needs.
- **ASIP** is a national organization that establishes and promotes policy and practice for professionals who respond to infant and child death, and is committed to bereavement support, risk reduction and prevention services.
- **PRAMS** is an ongoing, state-specific, population-based surveillance system sponsored by the U.S. Centers for Disease Control and Prevention (CDC) that is designed to identify and monitor selected maternal behaviors and experiences before, during, and after pregnancy. PRAMS can provide the data to monitor maternal behaviors, evaluate, and inform infant safe sleep programs.



Whether contributing support to maternal and child health programs, promoting policy and practices to professionals who respond to infant and child death, or providing data to programs, collaboration among maternal and child health programs (i.e., ASIP, PRAMS) at the national and state levels is necessary to achieve data-driven decisions that address infant safe sleep programs.

PRAMS PARTICIPATION, 2012

PRAMS represents approximately 78% of all U.S. live births.



MICHIGAN

Public Health Concern: Michigan infant mortality data indicated that almost one-third of infant sleep-related deaths in Michigan involved sharing a sleep surface with other children or adults. Although a robust Back to Sleep Campaign had been in place for over a decade, the rate of infants being placed on their back for sleep could be improved upon.

Action

In 2004, a broadly representative Infant Safe Sleep Work Group was convened to develop consistent statewide messages and strategies to inform families and caregivers about unsafe sleep practices. PRAMS findings about the prevalence and demographics of bed sharing and infant sleep position trends were used to outline the tasks for the work group. In addition, the findings provided the basis for focus groups, targeted education strategies and the development of infant safe sleep materials.

In 2005, the Michigan PRAMS program released data from 2002 showing that 61.0 percent of Michigan women reported bed sharing with their infant and 39.0 percent reported never bed sharing. The overall prevalence of back sleeping increased from 38.2 percent in 1996 to 69.3 percent in 2002. The prevalence of back sleeping in the Black population was about 1.2 times lower than in Whites.

In May 2011, a follow-up PRAMS report was released. This report described trends of sleep position and bed sharing utilizing data from 2001-2008. The data indicated that there has been no significant change in these behaviors during this time period.

Impact

PRAMS findings have been and continue to be used as an impetus to develop, strengthen and enhance infant safe sleep efforts. Whenever possible, efforts focus on institutionalizing the message and creating systems change through rules, policies, procedures and standards of care. Change is sustained through evaluation and ongoing assessment of the risks.

With the release of the expanded 2011 American Academy of Pediatrics guidelines for safe infant sleep, the PRAMS findings are being used to revise the education materials and education strategies. PRAMS data has also been valuable in developing successful grant proposals to support these efforts.

Projects include:

- Infant Safe Sleep in the Hospital Setting: A Nursing Practice Model
- Infant Safe Sleep in the Pediatric and Obstetrician Office Setting
- Revision of Michigan's childcare licensure rules to reflect AAP recommendations
- Development of education materials, including brochures, posters and DVDs

FLORIDA

Public Health Concern: In Florida, like the rest of the United States, there are well documented disparities in rates of infant mortality between racial and ethnic groups. For example, the Black infant death rate for all SUID is more than two times the SUID rate among White infants. Known risky infant sleep behaviors associated with SUID include infrequent back positioning when putting an infant to sleep and frequent bed sharing between parent and infant.

Action: Core PRAMS questions include frequency of back positioning and Florida has selected additional PRAMS questions on frequency of bed sharing.

- Florida used their PRAMS data to assess the relationship between not using the infant back sleeping position and bed sharing. This analysis indicated these two behaviors were not related when examined in conjunction with multiple factors. The lack of association demonstrated one general message cannot be used to address all risky

infant sleep behaviors; rather, these two sleep behaviors require distinct messaging and intervention strategies.

- In addition, Florida used the PRAMS data to look at maternal characteristics associated with risky infant sleep behaviors, including significant differences between racial groups. The results showed that Black mothers were more likely to infrequently use the back position and bed share. The data also indicated unwanted or unplanned pregnancy and traumatic stress were associated with infrequent back positioning among Black and White mothers. Maternal age, being unmarried, breastfeeding and partner-associated stress also were significantly associated with a greater likelihood of frequent bed sharing. Differences also were documented within racial groups. For example, Black mothers who reported depression were seven times more likely to frequently bed share than Black mothers who did not. These findings suggest that targeted messaging may maximize prevention efforts.

Impact

- These findings have been used to inform a statewide education initiative on SIDS/SUID prevention. Florida's initiative includes the development and distribution of educational materials, a position paper on bed sharing to promote consistent messages across programs at a state and local level, and online provider training to disseminate the results of SUID research studies.
- In addition, the Florida Department of Health shared the analysis results with local Healthy Start coalitions that provide direct services to individuals and communities, so their infant sleep messaging can be more targeted.

Additional State Examples of Data Driven Decisions:

- In **ARKANSAS**, a study of the factors associated with infant sleep position using PRAMS data resulted in five key program recommendations: reinforce back sleep position at prenatal visits; provide education in the hospital setting after the birth; have female leaders from Black communities serve as advocates for change; target other family members; and develop social marketing capacities.
- In **HAWAII**, PRAMS data on maternal characteristics associated with not placing infants to sleep on their backs suggested that WIC would be an ideal location for educational interventions, given that mothers with risk factors associated with not placing their infants to sleep on their backs were more likely to utilize WIC services.
- In **LOUISIANA**, PRAMS data were used to set priorities for statewide media messaging and will aid in the creation of a media campaign aimed at increasing awareness of a safe sleep environment and addressing barriers amongst the target populations.
- In **NEW JERSEY**, PRAMS data indicated that culturally competent outreach and education through primary health

care providers, childcare facilities and public health programs could serve as the vehicles for penetrating all social groups with the Back to Sleep message to overcome barriers to awareness.

- In **VIRGINIA**, PRAMS data on infant sleep position, bed sharing and infant smoke exposure were used to support a grant application to provide statewide training of birth hospital nursing staff on modeling safe sleep practices to parents and developing hospital-based policies regarding safe sleep environment and practices.

How Can You Begin to Collaborate?

Information on how to access PRAMS data, archived SUID webinars co-sponsored by AMCHP and ASIP, as well as program information about the three organizations can be found at the following websites:

- **AMCHP:** www.amchp.org
- **ASIP:** www.asip1.org
- **PRAMS:** www.cdc.gov/PRAMS/CPONDER.htm

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