North Carolina Makes Strides to Reduce SIDS, but Challenges Lie Ahead

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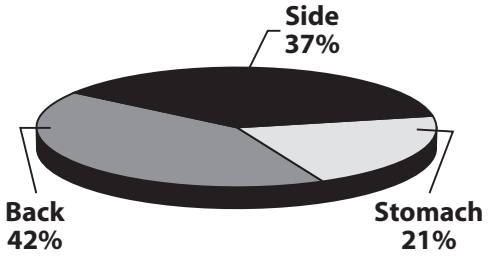
Sudden Infant Death Syndrome (SIDS) is the third leading cause of infant mortality in North Carolina. Five-year trends show that approximately 100 babies under the age of one year continue to die suddenly and unexpectedly in North Carolina each year.

The SIDS landscape is one in which North Carolina's rate has consistently exceeded the national rate. In 1988 the NC SIDS rate was 1.87 per 1,000 live births compared to the US rate of 1.4 per 1,000 live births. In the intervening thirteen years, SIDS rates have dramatically decreased. The state's lowest SIDS rate ever, 0.7 per 1,000 live births, was reported for 2002. From 1995 to 2002 the NC SIDS rate has fallen 36%.[1]

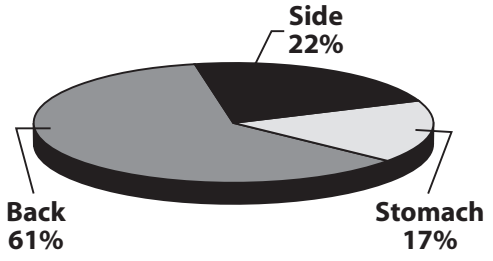
While this decline in SIDS is certainly good news, it tells only half of the story and should be viewed with cautious optimism. As with infant mortality, the SIDS rates reflect an unacceptable disparity among populations. African American infants are dying from SIDS at twice the rate of white infants. From 1998-2002 NC African Americans accounted for 41% of SIDS deaths, a rate of 1.35 per 1,000 live births, compared to the white rate of .66 per 1,000 births or 58% of SIDS cases. American Indians accounted for 1% of SIDS deaths, a rate of .83 per 1,000 live births, during this same timeframe.

Figure 1.
1998 Infant Sleep Position – NC PRAMS Data



Source: NC State Center for Health Statistics 2004

Figure 2.
2001 Infant Sleep Position – NC PRAMS Data



Source: NC State Center for Health Statistics 2004

Public education and awareness campaigns have contributed to reductions in SIDS rates. The reversal in the infant sleep positioning message from the prone to the supine or to the side by the American Academy of Pediatrics (AAP) in 1992 and the 1994 National Back To Sleep Campaign's reinforcement of this message resulted in a greater proportion of infants positioned on their back or side for sleeping and a corresponding 50% drop in SIDS deaths nationally.[2] The AAP revised its infant sleep position recommendation for healthy infants from stomach to back only in 2000. Closer to home, the statewide NC Back To Sleep Campaign, also launched in 1994, is credited with contributing to the more than 30% reduction in SIDS we have today.

NC Pregnancy Risk Assessment Monitoring System (PRAMS) data collected by the State Center for Health Statistics documents a significant shift in infant sleep position by North Carolina parents and primary caregivers since 1998.[3]

Both Figures 1 and 2 demonstrate that the back sleep position is the most commonly used position for sleeping infants, followed by the side. A comparison of sleep position changes from 1998 to 2001 shows a marked increase of 19% for infants placed on their backs to sleep with corresponding decreases in the side (15%) and, to a lesser degree, the stomach (4%) sleep positions. The NC Back To Sleep Campaign goal, in keeping with the national goal, is to reduce the prone sleep position for infants to not more than 10%.

According to PRAMS data, two-thirds of whites and Latinos place their infants on their backs for sleeping, a practice that is much less common among African Americans (43%). African Americans are much more likely to favor the stomach sleep position for infants (24%) compared to whites (14%) or Latinos (8%). The side sleeping position for infants is also preferred more often among African Americans (32%) and

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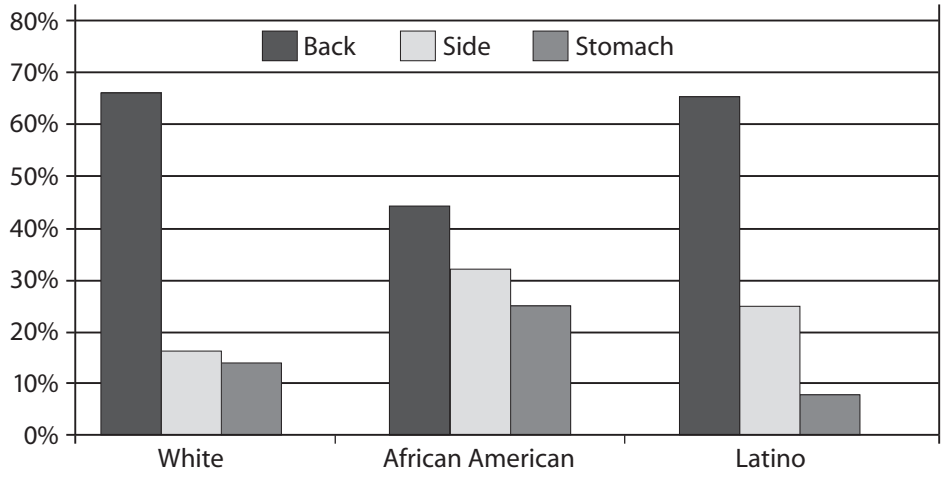
Figure 3.
2001 Infant Sleep Position by Ethnic Group – 2001 PRAMS Data



Source: NC State Center for Health Statistics 2004

Latinos (25%) and occurs less frequently among whites (18%). Cultural practices, the influence of a grandmother in the household, medical conditions, parent's preference, modeling and parent education by medical professionals such as newborn nursery staff, and experience with a previous infant contribute to infant sleep position practices. Concerns about choking, plagiocephaly (flat heads), or a bald spot are oftentimes barriers to placing babies supine for sleeping.

Epidemiological and PRAMS data are critical elements for the NC Back To Sleep Campaign's social marketing strategies and are used to identify audience and sleep position messaging. Statewide data depicting the distribution of SIDS deaths are used to target media markets at the county level. These data point to a continued need to inform North Carolinians about SIDS risk reduction and to particularly engage the African American community in infant safe sleep strategies. State efforts are challenged to keep up with the demand for culturally competent Spanish language SIDS education and outreach for Latinos.

SIDS is a Leading Cause of Deaths in NC Childcare

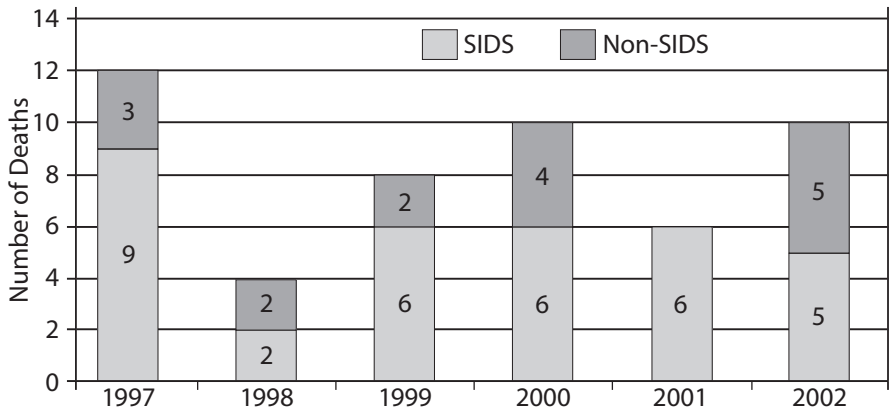
National research suggesting that a disproportionately high number (20%) of SIDS deaths occurred in childcare sounded an alarm that prompted the targeting of childcare providers for SIDS risk reduction education and training. Researchers found that, while more infants were positioned for sleep on their backs in childcare, those succumbing to SIDS in childcare were more likely to have been placed on their stomachs for sleeping. Of the smaller subset of babies (N=99) for whom information about the length of time in childcare was available, one-third had died during their first week in childcare and one-half of these occurred on the first day.[4] Unaccustomed prone sleepers may be at a higher risk when positioned prone. Approximately 7% of North Carolina's SIDS deaths occur in childcare settings, a figure one might expect to observe given Census data and the amount of time infants spend there.

The state has almost 16,000 infants in licensed childcare, according to the NC Division of Child Development (DCD). Figure 4 illustrates that two-thirds of all deaths from 1997 to 2002 in NC childcare were attributed to SIDS. During this six-year period, there were 34 SIDS deaths and 16 deaths due to other causes.

SIDS Risks Present in NC Childcare

Observational and survey data collected in 2002 prior to the implementation of the Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) initial training, and prior to SIDS risk-reduction legislation in 2003, showed that SIDS risk factors were present in a sample of 217 regulated childcare centers and homes in North Carolina. Sleep position varied and included side, stomach, back, and sitting. Babies

Figure 4.
Proportion of SIDS to Non-SIDS Deaths in North Carolina Childcare from 1997 to 2002



Source: NC Division of Child Development

slept in a variety of places such as cribs, bassinets, playpens, bouncy-seats, car seats, and, in the case of one childcare home, on a sofa. The immediate sleep environment contained toys, stuffed animals, and excess bedding. Although rare, there was evidence of cigarette smoke in one family childcare home. Very few facilities had a written safe sleep policy in place. Though some caregivers had attended SIDS workshops, childcare providers identified SIDS training and policy development as needed and most expressed a desire to have educational print materials for parents.

Media is a Catalyst to Combat SIDS

A cascade of recent events has impacted how North Carolina's babies are sleeping at home and in childcare. SIDS has been in the media spotlight frequently in the past year, not only as a news feature but also in the halls of the NC General Assembly. Consequently, we are witnessing a ripple-effect of safe sleep policies being implemented in a variety of childcare settings and adopted in private homes.

Beginning February 16, 2003, the Raleigh *New & Observer* published a three-day investigative series entitled *Case Closed: Deaths in Day Care*[5] that focused attention on SIDS, the unauthorized administration of medication in childcare and the operation of unlicensed, illegal childcare in the state. A strongly worded editorial on February 19, described the shortcomings in North Carolina's regulation of day care center's as not only unacceptable, but despicable! This editorial demanded that the Governor and legislative leaders toughen childcare oversight and regulation and outlined several strategies to address health and safety concerns in the state's more than 9,000 licensed childcare facilities. To tackle SIDS, the *News & Observer* called for a state law requiring that infants in day care not be put to sleep on their stomachs. Representative Martha Alexander, a stalwart child advocate, was quick to act, and by late February House Bill 152, the precursor to the NC SIDS Law, had been filed.

The NC SIDS Law

December 1, 2003 is an historic moment in the state's battle against SIDS. North Carolina joined the ranks of a handful of states legally mandating that licensed childcare providers position babies 12 months of a age or younger on their backs for sleeping, having written policies in this regard, and obtaining training for childcare workers. House Bill 152 expanded General Statue 110-91 pertaining to mandatory childcare standards and was ratified as GS 110-91-15. The NC Prevent SIDS law includes a waiver provision based on medical need, for infants six months of age or younger. The law also allows a parent or legal guardian to waive the back to sleep requirement for infants older than six months. This allowance represents a political compromise and is not a best practice in accordance with recommendations of the AAP and the National Resource Center for Health and Safety in Child Care. Nonetheless, other elements of the law do reinforce standards designed to lower SIDS risks in childcare, including the mandate to develop a written safe sleep policy and to discuss it with parents prior to the child's enrollment. The type of required SIDS-related training was unspecified in the law.

NC Childcare Licensing Rules

The next step was to codify the more broadly written law into specific licensing rules for childcare providers. Developing guidelines for everyday practice is the responsibility of the NC Child Care Commission (CCC). The Commission is comprised of legislative appointees and includes childcare providers, community leaders, a pediatrician and Division of Child Development (DCD) staff. The Commission's rules committee, faced with the task of weaving legal requirements into childcare licensing rules, included a subset of Commission members, child advocates, legal counsel, DCD staff members and this author. Rule changes affecting behaviors and environmental factors associated with SIDS risks were proposed, reviewed by the Commission, tweaked, and then posted for public comment for two months from December 2003 to February 13, 2004. Revisions to the proposed rules incorporated feedback from the public review process and were then subjected to legal review by the Rules Review Commission in March and entered into the Code by the Office of Administrative Hearing in April. The resulting licensing rules went into effect May 1, 2004.

Of significance, the rules pertaining to safety and sanitation include prohibitions on tobacco use around children in family childcare homes and vehicles when transporting children, where none had existed heretofore. Secondhand smoke more than doubles the chances of SIDS, exacerbates asthma, is an allergen, and triggers respiratory infections. Tobacco products are a leading cause of childhood poisoning.

The revised licensing rules addressing infant/toddler sleep safety and SIDS apply to childcare providers licensed to care for infants 12 months of age or younger and are summarized as follows:

1. An infant 12 months of age or younger is to be positioned on the back for sleeping unless a waiver states otherwise. A physician waiver exempting back to sleep for infants six months of age or younger is required. Childcare providers may choose to implement a parent waiver for infants older than six months.
   Note: *The Alternative Sleep Position Waiver—Physician Recommendation* form, developed by the DCD, must be completed by the child's primary care physician in the event a medical condition necessitates it. The waiver states the medical reason for a sleep position other than the back and the recommended alternative sleep position must be identified.
2. A notice indicating that a waiver is in effect and stating the recommended sleep position must be posted near the child's crib. The signed waiver is to be kept in the child's file.
3. A written safe sleep policy or poster must be prominently posted and this information communicated to parents before a child is enrolled. The policy must be discussed with

parents of currently enrolled infants within 30 days of the rules' effective date.
4. The crib, bassinet or playpen will have a firm padded surface.
5. Baby's head or face shall not be covered.
6. Tobacco products can not be used at any time children are in care; and smoking or use of tobacco products is not allowed indoors when children are in care, or in a vehicle when children are transported.
7. The room temperature where babies sleep cannot exceed 75ºF.
8. Sleeping babies must be visually checked and the frequency of checking and observations documented. This record must be kept on file for one month following the reported month.
9. Awake infants shall have a daily opportunity to play while on their stomachs.
10. The Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) training is the designated training.
11. Owners/operators/directors, lead infant teachers, substitutes and volunteers counted in the child-to-staff ratio must obtain ITS-SIDS training. Providers must renew their ITS-SIDS certification every three years. New hires shall receive ITS-SIDS training within four months of hire or within four months of the rules becoming effective, whichever comes later.

ITS-SIDS Training Project

The Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) Project is a train-the-trainer initiative developed as part of the NC Back To Sleep Campaign, a program of the North Carolina Healthy Start Foundation. It adheres to the AAP recommendations, national child health and safety gold standards and best practices aimed at reducing SIDS. ITS-SIDS was initially funded for two years by the NC Division of Child Development on July 1, 2002—almost one and a half years before the NC SIDS law went into effect. Given the sequence of events and training needs, the Division expanded funding for Phase Three from December 1, 2003 through June 30, 2005.

Project goals are to: (l) introduce a safe sleep standard in NC childcare, (2) develop a cadre of certified ITS-SIDS trainers and (3) provide contact hour credits for childcare providers. The objective is to train 180 certified ITS-SIDS trainers who would, in turn, train 14,500 childcare providers over the course of the three years. ITS-SIDS trainers are made up of Child Care Resource and Referral staff, Smart Start Partnership staff, Child Care Health Consultants, Cooperative Extension Service Agents, Migrant Head Start staff, childcare directors and private trainers.

With changes in the legal and licensing requirements the demand for ITS-SIDS training across the state has skyrocketed. A total of 208 ITS-SIDS trainers have been certified. As of May 28, 2004, over 17,950 childcare providers have received ITS-SIDS training and 982 trainings have been scheduled or completed. While not all North Carolina counties have a resident ITS-SIDS trainer, all 100 counties do have training coverage. A fourth train-the-trainer series is planned for fall 2004 to address trainer attrition and to provide updated information.

How Will the NC Licensing Laws Affect Healthcare Providers?

There are several areas where physicians, perinatal healthcare providers and parent educators are impacted by the sleep safety and SIDS risk-reduction childcare requirements. First, physicians may be approached by parents to complete the *Alternative Sleep Position Waiver—Physician Recommendation* form. This waiver exempts a child 12 months of age or younger from being placed on his or her back to sleep based on a medical condition and specifies the recommended sleep position for that child. The baby's doctor is also asked to indicate the time frame for which the waiver applies. The onus of responsibility for the baby's sleep safety in childcare is shared by both the caregiver and the baby's primary care physician.

Parent-physicians desiring to waive the back sleep position for their child and attempting to sign the medical waiver themselves, muddy the legal waters and place the caregiver in an awkward situation. This scenario has already occurred in North Carolina and in other states. In Illinois, for example, providers are instructed to tell the parent-physician that they must choose. Either they assume the role of parent or that of doctor, but not both.

Particularly striking is the juxtaposition between what parents observe in the hospital or are taught by newborn nursery staff and what is played out in the childcare arena. Tension around the issues of infant sleep position, swaddling, use of sleep positioning devices such as blanket rolls or wedges and co-sleeping twins is a dynamic situation already occurring downstream from the hospital setting and now surfacing in childcare settings.

Not all of North Carolina's hospital nurseries practice the back to sleep standard of care for healthy babies. Some, but not all, of the state's Neonatal Intensive Care Units (NICU) have guidelines for transitioning infants from their stomach or side sleep position to their back; this should be as routine as the testing done for car seat safety among preemies. Similarly, educating about infant sleep safety and transitioning to the back sleep position should be incorporated into routine hospital practices as part of preparing all infants for discharge.

Parents are being taught in the hospital to swaddle infants for comfort and for security, but are they being informed about the signs of overheating, a SIDS risk factor? Are they instructed about when to discontinue swaddling? When parents insist that their four-week, six-week, or three-month old infant be swaddled in childcare, providers are in a quandary. Is swaddling helpful or harmful at these ages? The likelihood of overheating increases for a swaddled child. Furthermore, is the childcare provider using correct swaddling techniques that will prevent the blanket from covering the baby's head?

Bed sharing or co-sleeping with a parent or with a sibling poses dangers to infants by increasing the likelihood of SIDS, overlay (parent or sibling rolling onto infant), suffocation, overheating, entrapment, and injury due to falls from a bed without railings.

The pros and cons of co-sleeping are extremely controversial.[6] Breast feeding advocates promote bed sharing while professionals involved in SIDS risk-reduction education and sleep safety discourage it.

Data suggest that twins are at a greater risk for SIDS due to several factors: being born with a lower birth weight, a shorter gestation, and more complications during pregnancy. The co-bedding of twins in hospitals, at home, and in childcare settings remains a complex issue. Hospital practices for twin sleeping arrangements influences the infant sleep practices that parents adopt at home.[7] In North Carolina childcare, crib sharing among infants—even twins—is a violation of childcare licensing rules, yet parents have sought and have obtained a physician's waiver to allow this practice. In one case the physician stated there was no medical reason for co-sleeping the twins, but that the parent had requested it. Again, the safety of the infants, the reasoning of this decision, and the legality of this action are called into question.

SIDS Risk Reduction in Childcare Reaches Parents

One favorable consequence of the safe sleep standards now required in NC childcare is that caregivers are informing parents about the steps they are taking to reduce SIDS risks. This has a spillover effect and extends the arm of SIDS awareness from the childcare setting into the infant's own home. Indeed, many of the ITS-SIDS trainers are being asked by childcare providers to present at parent orientations or to conduct workshops with parents. Providers can share free educational materials with parents that are developed and distributed by the North Carolina Healthy Start Foundation.

Childcare providers are also taking the safe sleep and SIDS risk reduction message home. Many professional childcare workers are themselves parents or grandparents. Evaluations from their ITS-SIDS training show they plan to adopt the recommendations in their personal lives and to share the information with others.

Growing National Efforts to Address SIDS

The American Academy of Pediatrics has recently reconvened their task force on Infant Sleep Position and SIDS to reassess SIDS-related research and to address issues such as hospital nursery guidelines, waivers in childcare, swaddling and co-sleeping. A position statement updating their 2000 recommendations[8] is expected in autumn 2004. Hospital nurseries and Neonatal Intensive Care Units (NICUs) nationwide are re-examining their sleep position guidelines in light of the earlier standards set forth by the AAP. And, the AAP together with the National Resource Center for Health and Safety in Child Care and other national SIDS organizations has initiated a nationwide "Back To Sleep Campaign" for childcare facilities and has incorporated elements of North Carolina's ITS-SIDS training curricula. The AAP is partnering with the National Conference of State Legislators to promote safe sleep/back to sleep and SIDS risk reduction legislation in states across the county.

North Carolina is Leading the Way in SIDS Risk Reduction

North Carolina is an active leader in SIDS risk reduction in childcare. The state has adequate SIDS-related legislation, carefully revised licensing rules, a robust ITS-SIDS training program and an active Back To Sleep public education and awareness media campaign in motion. Networking occurs on a national level and statewide provider and parent education is fostered through the solid cadre of ITS-SIDS trainers. However, challenges and gaps remain, particularly in the areas of developing and sustaining more in-depth and interactive parent and grandparent SIDS risk-reduction interventions. There is a pressing need to competently address targeted SIDS risks for African Americans and among our growing Latino population and to make culturally and linguistically appropriate outreach available to Latino childcare providers and families. And there remains a need for hospital nurseries and NICUs across the state to convey and model a clear and consistent safe sleep/back to sleep message to parents.

Limitations on workplace tobacco use in childcare settings and growing awareness among childcare providers and parents via the ITS-SIDS training that smoking triples the SIDS risk (babies' secondhand smoke exposure doubles it) may stimulate an increased demand for smoking cessation services. Healthcare providers can play a significant role in reinforcing information about the link between SIDS and smoking. Counseling women not to smoke or to avoid secondhand smoke during pregnancy is an essential first step to combating SIDS. The relationship between pre-term/low-birth weight births and SIDS needs to be more clearly understood. This information should then be conveyed to women and families.

While we have a steady compass and a roadmap to help plot our fight against SIDS, only time will tell the extent to which recent policy changes will impact the tragedy of SIDS in childcare and possibly in family homes. It is clear that too many North Carolinians have experienced heartbreak because of SIDS and that we must adequately support community-based efforts to promote infant/toddler sleep safety and SIDS risk reduction in culturally and linguistically appropriate ways for families, other caregivers, and for healthcare professionals. More can and should be done to inform parents and caregivers that lowering SIDS risks begins before the baby is born as well as afterward. **NCMJ**

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