BUREAU OF MATERNAL, INFANT
AND REPRODUCTIVE HEALTH

BELIEFS AND PRACTICES REGARDING SUDDEN INFANT DEATH SYNDROME (SIDS) RISK REDUCTION AMONG AFRICAN AMERICAN MOTHERS, FATHERS, AND CAREGIVERS IN NEW YORK CITY

Summary of SIDS Focus Groups

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Background

After ten years of an ongoing, aggressive "Back to Sleep" campaign, Sudden Infant Death Syndrome (SIDS) rates have lowered in the general US population but have remained relatively unchanged in the African-American community. African American babies in the U.S. are now twice as likely as white babies to die from SIDS. These racial disparities in SIDS deaths are even greater in New York City.

In a recent study conducted by the Infant Mortality Case Review Committee (IMCR), directed by the Bureau of Maternal, Infant and Reproductive Health (BMIRH), New York City Department of Health (NYC DOHMH), the racial disparity in SIDS deaths in New York City was found to be alarmingly high. The IMCR reviewed autopsy report summaries of 69 SIDS deaths in New York City for 2000-2001, and found that African American babies were 14.3 times more likely to die of SIDS than white babies. In addition, infants born to teen mothers ($\leq$ 19 years old) and mothers 20-24 years were 9.0 and 4.4 times more likely to die of SIDS, respectively, than infants born to mothers 25 years and older. Nearly half of infants that died due to SIDS were in the care of an extended family member, babysitter or in day care.

Therefore, BMIRH, NYC DOHMH set out to conduct qualitative research to inform the development of an education and outreach campaign to target the babies who continue to be at higher risk of SIDS – those who are born to African American young mothers of lower socio-economic status.

With the expectation that many of these young moms are raising their infants with the support and influence of caregivers (the babies' grandmothers, aunts, uncles, and other older adults) as well as the babies' fathers, research was structured to understand the attitudes and behaviors of all three groups – moms, caregivers and fathers of babies 12 months and younger.

Research Objectives

The overall objective of the research was to inform the development of an education campaign to reduce the incidence of SIDS risk behaviors of young African American mothers and other people who participate in childcare (either directly, or through their influence on young mothers) – the caregivers and young fathers.

Specifically, research gathered an understanding of the target audiences'

- Awareness of SIDS and SIDS risk behaviors
- Engagement in SIDS risk behaviors
- Perception of trustworthy sources of information and advice, particularly for health and safety issues such as SIDS
- Awareness of and reactions to the "Back to Sleep" campaign, and
- Reactions to a SIDS "Back to Sleep" brochure designed by the national Back to Sleep campaign (see Appendix B)

The research discussions with the young mothers, fathers and caregivers were designed to help determine the most effective campaign for reducing the SIDS risk as well as the most effective methods for reaching the target audience.

Research Methodology

Focus groups - qualitative research

In order to achieve the above objectives, BMIRH fielded a qualitative research study targeting the key populations. The research utilized focus groups to create an intimate atmosphere for respondents to share their knowledge and opinions.

Through a process of exploratory questioning of respondents, and follow-up probing of their responses, the focus group interviews provided an understanding of the underlying attitudes, behaviors and values which shaped respondents' opinions and perceptions about infant care and the current impact of the SIDS information and outreach campaign. The flexibility of the loosely structured interviews allowed for the pursuit of unanticipated issues that emerged as relevant tangents during the discussions.

The focus group interviews were conducted in community based organizations situated within the targeted communities of Harlem and Brooklyn, which further ensured a level of comfort for the respondents.

The groups were held:

- January 27, 2004 at the Northern Manhattan Perinatal Partnership at 127 W. 127th Street, Harlem; and,

- January 29, 2004 at Church Avenue Merchants Block Association, Inc. (CAMBA) 19 Winthrop Street (Flatbush) Brooklyn.

A total of six, two-hour focus groups were conducted in January 2004. Two groups were held with each of the following groups: young mothers, young fathers and caregivers of infants. A total of 20 mothers, 16 fathers and 22 caregivers were interviewed.

Recruiting

Typically, there are impediments to conducting research with an "untraditional" audience (e.g., difficult-to-reach, low-income, or disenfranchised individuals who are often not part of mainstream social structures). In addition to the logistical challenges of locating these audiences, it is often difficult to ensure attendance and participation in discussions around sensitive issues, such as self-image and lifestyle. Understanding these potential barriers, an exhaustive recruiting campaign was devised, reaching out to health care professionals, community based organizations, perinatal organizations, faith based organizations, case workers, district public health offices and alike. Recruitment included a mailing to over 100 partner organizations and a follow-up telephone call. In addition to

asking professionals to reach out to their colleagues and consumers, BMIRH designed colorful and compelling posters that BMIRH staff and researchers posted heavily throughout the target communities including braiding salons, barber shops, restaurants, clothing stores, community centers, etc. (See Appendix A.) To overcome recruiting challenges, BMIRH staff also visited pediatric clinic waiting rooms and community based organizations to actively recruit and screen potential participants on-site.

Potential respondents were asked to call a central number and were then screened over the phone by a BMIRH employee to determine if they fit the recruiting criteria. Respondents that fit the screening criteria were told the time, location and address of the appropriate focus group. In addition, qualified respondents were mailed directions and instructions, and received two reminder phone calls.

Respondent incentives

Respondents were originally offered $25, a two-ride Metro Card, and food and refreshments for their participation in the two-hour focus group. When recruiting enough participants (particularly young fathers) proved to be difficult, BMIRH was able to raise the incentive to $50. This helped considerably in attracting respondents.

Screening criteria

The specific recruiting criteria for the target populations for the study were:

Mothers:

- Between the ages of 18 and 22
- Baby 12 months or younger at time of recruitment
- Black woman of African American or Caribbean descent
- High school education or below (this criteria was altered to allow for some college education)
- Screened to not have suffered the loss of an infant to SIDS
- Not currently involved in a parenting class (where SIDS education would be encountered)

Fathers:

- Between the ages of 18 and 25
- Baby 12 months or younger at time of recruitment
- Black man of African American or Caribbean descent
- High school education or below (this criteria was altered to allow for some college education)
- Screened for significant personal involvement with child's care, based on frequency of care (at least three times per month) and basic knowledge of the infant's feeding routine (ineligible if uncertain whether child was primarily breastfeeding, taking formula, or eating solid food)
- Screened to not have suffered the loss of an infant to SIDS
- Not currently involved in a parenting class (where SIDS education would be encountered)

Caregivers:

- Grandparent, aunt, uncle, godparent, etc. who takes care of a relative's baby
- Baby 12 months or younger at time of recruitment
- At least 40 years old
- Black, African American or Caribbean descent
- High school education or below (this criteria was altered to allow for some college education)
- Screened for significant personal involvement with child's care, based on frequency of care (candidate ineligible if less than three times per month), voluntary nature of care (ineligible if a paid professional caregiver), and basic knowledge of the infant's feeding routine (ineligible if uncertain whether child was primarily breastfeeding, taking formula, or eating solid food)
- Screened to not have suffered the loss of an infant to SIDS

Demographic data

Demographic data was collected from all respondents in exit survey at the conclusion of each focus group. Overall, the participants closely matched the initial screening criteria for the target population. A high majority (81%) of respondents identified themselves as African American. 10% chose Black Caribbean as their ethnicity and the remaining identified as Hispanic/Latino, Native American or other. Almost half of the respondents (47%) reported having a high school diploma or GED, 21% had some high school, 26% had some college (2 years or less), 5% had more than 2 years college with no college degree, and 2% had a college degree. Most respondents were born in the U.S. (82%). The mean age of the young mothers who participated in the groups was 20, the dads' mean age was 23, and the caregivers' mean age was 45.

While grandparents constituted the largest percentage of participating caregivers (40%), followed by aunts (27%), other extended family members (cousin, great aunt and godmother) and family friends also met the screening criteria and participated in the caregiver groups. An overwhelming majority of caregivers (82%) was female.

Executive Summary

Overall, respondents – especially young mothers – are generally aware of SIDS and most of the recommended SIDS precautionary practices. However, in day-to-day childcare, moms, dads and caregivers say their top concerns with a new baby are more immediate and practical challenges such as having enough money, getting adequate and restful sleep (for the baby *and* the parents or caregiver), seeing to the baby's immediate physical, emotional and developmental health, negotiating the social services system, and managing the changing relationships that a new baby brings. These very present and daily concerns generally supercede more abstract and hypothetical concerns such as SIDS. When asked about their concerns, none of the respondents specifically mentioned SIDS as an immediate concern unaided by prompting from the researchers.

In general, mothers, fathers, and caregivers all develop relationships with the child that are characterized by pride, love, protectiveness, and a desire to "spoil" the new baby. These attitudes often motivate sleep practices that are focused on the baby's maximum comfort and closeness to loving adults in the short term, again superceding practices such as back sleeping and independent (crib or bassinette) sleeping, that are commonly viewed by the participants as less comfortable and less emotionally gratifying for both infants and adults.

Practical and emotional relationships between mothers, fathers and caregivers are complex and sometimes challenging during the first year after the birth of the child. In general, grandmothers of the baby, the mother's mother in particular, assume an increasingly important and active role in the new mothers' lives with the birth of the new child. On the other hand, young mothers and young fathers – whether married, living together, or living separately – describe varying degrees of contact and cooperation in childcare, most often depicting dynamic relationships that are frequently fraught with tension regarding what is best for the baby. When young mothers and young fathers disagree, it is often the child's grandmother whose trusted opinion and proven experience can break the deadlock.

The research suggests young mothers and caregivers are vitally important individuals to reach in any SIDS awareness and prevention campaign. Young fathers, while many may be actively or passionately engaged in decision-making about daily child care, infrequently have the final authority or the same depth of practical engagement in sleep practices as young mothers and caregivers. Based on the findings, it is recommended that future campaigns focus on young mothers and caregivers, and appeal to their most immediate daily concerns. At the core, these concerns are focused on the personal, loving and giving relationship between the adult and the child, and are informed by what participants describe as "doing what works," "knowing your own child," "doing what my mom did," and following parental "instinct." SIDS messaging content and routes of transmission must align with the values, forms of knowledge, forms of trust, and existing practices that accompany these concerns and attitudes.

Overview of Major Findings

I – Primary Concerns with a New Infant

With the introduction of a new baby in their lives, moms, dads and caregivers share similar top of mind concerns:

Finances

All groups say that one of their biggest sources of stress with a new baby is having enough money for the child's essentials: food, diapers, clothing, shelter, etc.

"Pampers! Paying for Pampers!" – Mom in Brooklyn

Young dads in particular say that providing for the new child is their primary responsibility. Many are anxious to find employment and some are working two jobs.

"I am working two jobs. I want her to go to college. Everything has to be ready." – Dad in Harlem

Health issues

A second primary concern that respondents raise is the infant's physical, emotional and spiritual health. The new moms and dads speak of being both awed and overwhelmed by the enormity of being a parent and the responsibility they have for this new life. Moms say that they are often checking to make sure the baby continues to breathe, especially during the first few weeks of their baby's life. All respondents say they want to make sure their baby feels loved and comforted, and the dads in particular describe the need to establish an intimate connection with the baby.

"Sometimes I just poke him to make sure he is alive." – Mom in Harlem

"I am just buggin' about the baby thing. I am so protective of her, I freak out when the littlest thing happens, like she gets a rash on her face or something." – Dad in Brooklyn

"When I hold the baby she falls asleep because it's a spiritual connection. Your heart starts beating at the same time." – Dad in Harlem

"You gotta constantly watch your kids and give them love." – Caregiver in Brooklyn

Social services

Respondents describe the challenges of negotiating the social services system. Moms say they feel constantly scrutinized and worry about health care professionals and social workers judging them and not respecting them. Moms and caregivers describe how

navigating the social services system is an important part of their lives – making sure they receive the benefits and health care their family needs.

"The city doesn't know what they are talking about. Don't trust nobody but yourself." – Mom in Harlem

"My son fell down the stairs and had to have stitches and everybody looks at me like I am an unfit parent." – Mom in Brooklyn

"The state, you have to deal with the state. And that's not easy." – Caregiver in Harlem

Relationships

Finally, all respondents say that with the new baby, relationships with the mother, father of the baby, and the grandmother become more important – increasingly relied upon and often more stressful. The infant becomes a fulcrum of these relationships.

Most importantly, grandmothers of the new baby (the mother's mother in particular) assume an increasingly important and active role in the mothers' lives with the birth of the new child.

Safe sleep – not named as a top concern without prompting

While discussing primary concerns, none of the respondents mentioned safe sleep for the baby as a top of mind issue unless prompted by the researcher. Moms, however, cite getting enough sleep (for themselves and the baby) as a challenge during the first months of an infant's life.

II – Changing Relationships – The influence on the young mother

Moms

Relationship to baby: The young mothers we spoke with love and adore their new baby with a passion. They describe an intense physical attachment to the child.

"She (the baby) was just inside my body!"– Mom in Harlem

Relationship to father of baby: The moms describe varying degrees of contact with the father of their baby, and a range of relationships. Whether the father was living with them or not, their relationship was often fraught with tension regarding what was best for their infant.

Relationship to their own mom (grandmother/caregiver): The grandmothers take on a more active role in the new mother's life with the birth of a child. These caregivers are

relied upon as a consistent, free, non-judgmental source of information and support, and thus have a very significant amount of influence over the infant's care.

"I talk to my mother because she's not going to judge me for not knowing what to do. Anybody else would say, 'Oh you should have done this or shouldn't have done that.'" – Mom in Brooklyn

Dads

Relationship to baby: Dads express a tremendous amount of love for their babies, but the majority of them are not able to spend comparable amounts of time with their babies and are therefore not as deeply involved in the child's care. These dads are often working one or two jobs to financially support the baby and their "baby mom," and many are not living in the same house as the mother and child.

"I don't get to see my son as much as I want, because working the daily grind takes up the time." – Dad in Brooklyn

Being a father is a source of great pride and an important identity issue. As part of this new identity, fathers stress the importance and weight of being financially responsible and serving as a good role model for their child.

" A daughter needs a father and needs a mother. She needs that learning from her mother – but from her father she needs to learn a sense of security." – Dad in Harlem

Relationship with mother: Maintaining a functionally effective relationship with the mother of the child is seen by these dads as important in order to maintain a link to the child.

"I'm lucky because she didn't take off to Georgia with my baby." – Dad in Brooklyn

"I want my baby to always know I'm his father." – Dad in Harlem

Caregivers

Relationship to baby: Caregivers define themselves as child-care experts, and they take pride in being the first resource on child rearing in their extended family. They have a deep sense of confidence in their ability to care for children. This role as an authority is a crucial, primary part of their identity.

"The first thing she (the mom) does when something is wrong is call uncle Sammy (me)." – Caregiver in Brooklyn

"I've been taking care of babies since I was 11 years old." – Caregiver in Harlem

Even those caregivers who are not related to the mom describe an intense "love bond" with the infant. Many speak of an increased sense of responsibility when caring for an infant that is not their own.

"It's an instinct to want to protect a child. You almost worry more if it's someone else's." – Caregiver in Brooklyn

Caregivers talk a great deal about their place in a generation of mothers and caregivers. In this way they feel as if they have earned their caregiving "stripes."

"My momma had eleven kids. I had seven. I know babies." – Caregiver in Harlem

This strong sense of parenting heritage and lineage is one reason that many describe their belief in and reliance on alternative, "home" or folkloric remedies. Caregivers also describe the importance of "intuition," "common sense" and "life experience" in caring for babies.

"I remember what my mom did for me and what I did for my baby." – Caregiver in Harlem

Finally, caregivers (and moms) say that it is important to understand that all babies are different and that one health care remedy or piece of advice will not work for every child.

"Sometimes, you have to try it all. If one thing doesn't work, you have to try another. Each child is an individual." – Caregiver in Brooklyn

III – Attitudes and Behaviors toward Sleep

Shared concerns about back sleep

Although nearly every respondent had heard about the importance of back sleeping (or had at least heard differences of opinion regarding the comparative safety of back sleeping) the overwhelming majority of respondents express many concerns about putting an infant to sleep on its back, particularly during the first few months of the child's life.

Respondents say they are resistant to putting a young infant on its back because of their belief that back sleeping brings the following problems:

Choking – Moms, and caregivers in particular, say that they believe it is dangerous to put a baby on its back because it could choke. Caregivers say they learned this when they were new mothers, and the young moms explain that they learn this from the caregivers. Both moms and caregivers say it also makes "common sense."

"It's obvious. If a baby spits up when it's sleeping on its back it can choke on its spit." – Mom in Harlem

"No, you don't put the baby on its back because it can choke." – Caregiver in Brooklyn

Fitful or poor sleep – Moms and caregivers say that babies are not comfortable sleeping on their backs and, therefore, do not sleep well. Respondents describe how the baby often won't sleep (or will only sleep fitfully) on its back and it's not until a baby is placed on its stomach that it can finally have restful, peaceful sleep.

"My baby just won't fall asleep on her back." – Mom in Brooklyn

"My daughter was complaining that her baby wouldn't sleep. I went over there and she had that baby on its back. I turned him over and he went right to sleep. He was uncomfortable." – Caregiver in Harlem

Essential discomfort – Moms and caregivers describe how a baby does not feel safe on its back. Many say that they've seen babies shake on their backs because they "feel like they are falling" and they have "nothing to grab onto." Again, respondents say this is intuitive and it's something they observe.

"On their backs they can't hold on to anything and they feel like they are falling. They get jumpy." – Caregiver in Harlem

Too exposed to the light – Moms and caregivers say that babies are uncomfortable on their back because the light on their face can be harsh for a newborn that has just emerged from the dark safe womb.

"On their back they are lying there with all that light in their eyes – no wonder they can't sleep, they need protection." – Caregiver in Harlem

Flat head and hair pulls – All respondent groups say that back sleeping can cause flat heads and bald spots in a baby. However, this is not as primary a concern for avoiding back sleep as is the fear of choking or bad sleep.

<u>Shared proclivity for co-sleeping</u>

The majority of respondents report that they co-sleep with their babies at least some of the time. Co-sleeping is viewed as a means of providing psychological comfort to the

child and the adult while simultaneously allowing the parent(s) or caregiver to carefully observe and monitor the babies' breathing and general health.

In general, moms describe wanting to be as close as possible to their baby during the first few months of its life. Most say their infant would fall asleep on their chest, and approximately half say they slept in the bed with their baby.

"You just want to be close to it because it used to be inside of you."
– Mom in Brooklyn

Many caregivers say that babies need to be close to them and to their mothers. They believe that a baby is comforted by their scent and by their heartbeat. Most caregivers say they sleep with the baby.

"Most babies, they need to touch somebody. They wake up and if there is somebody there, they go right back to sleep." – Caregiver in Brooklyn

"My grandson won't stand sleeping unless he is in bed with me."
– Caregiver in Harlem

Many young fathers who are actively involved in their child's lives and sleep habits share similar views regarding co-sleeping with moms and caregivers.

"I sleep with the baby. The baby sleeps better because of my body heat. She feels me right there, so she goes to sleep faster." – Dad in Brooklyn

In general, participants express a belief – particularly strong among caregivers – that co-sleeping is best for the baby because it allows the adult to closely monitor their breathing and readily respond to the infant's needs.

"I am more comfortable when I let the baby sleep with me. I can feel and hear their breathing. Its more comfortable for the baby and safe."
– Caregiver in Brooklyn

"I want to hear every little noise she makes." – Dad in Brooklyn

These beliefs – closeness and monitoring – lead parents and caregivers to question the logic and necessity of putting a baby to sleep in a crib. This is particularly the case when the caregiver does not live with the baby's mother and may not have a crib or bassinette in his or her own house. While moms are likely to have bassinets and/or cribs at home, many moms do not use these separate sleep options until the baby has reached the age of 3-4 months. Often financial constraints and small living quarters are barriers to the presence of a bassinet or crib in a household.

Most moms and caregivers say they do recognize, however, that co-sleeping must be done carefully or safely. They are aware of the possible dangers of a baby falling off the bed or an adult rolling over.

"When I have her next to me, I am so aware of her, I don't move an inch all night."
– Caregiver in Harlem

Moms – establishing initial sleep patterns

Moms are most concerned about a baby's sleep during the first few months of the infant's life. During the first weeks after birth, the mom is anxious that the baby will sleep at all, and is also concerned that the baby will sleep comfortably (and for increasingly extended periods).

Moms say they establish and cement baby sleep practices and routines shortly after they first bring the baby home from the hospital. This is the time, they say, when they rely heavily on their own intuition as well as the advice and oversight of their mother or caregiver to determine how the baby will sleep most comfortably and safely.

Moms learn back sleeping in hospital

All the moms mentioned without prompting from the researcher that they were "hammered over the head" in the hospital with the message to put their baby on its back. They say the nurses told them to put their baby on its back, and that the nurses continually placed the baby on its back while in the hospital. Many say they were given pamphlets and magnets and door hangers with the instruction to put the baby on its back. Several also recount having to sign an agreement before leaving the hospital to put their baby to sleep on its back.

"I had to sign something in the hospital saying that I would make my baby sleep on the back." – Mom in Brooklyn

"Me too. I had to take a 1 hour class before they would release my baby to me."
– Mom in Brooklyn

But moms commit to stomach sleep at home

However, by the time they had been at home for a week or so, most of the moms say they had decided to place their baby to sleep on its stomach. This was when they say they encountered the baby having difficulties falling asleep on its back, and received strong encouragement or instruction from their own mothers (caregivers) to place their baby on its stomach for the baby's safety and comfort.

"My mom said, 'What are you doing putting that child on his back…you want him to be terrified? Haven't I told you to put him on his stomach? That's what I did with you. That's what my mom did for me.'" – Mom in Harlem

"My momma says to put the baby on the stomach…all this on the back stuff is new, but what my mom did they did for generations and it worked fine." – Mom in Brooklyn

At this point, young moms begin to let go of the hospital instruction and find ways to care for the baby that fit with their intuition – their sense of what their own individual child needs as well as what meshes with the confident advice and instruction of trusted caregivers.

"You try and find what works, whatever makes them comfortable."
– Mom in Brooklyn

"The book says one thing but the child might not sleep that way."
– Mom in Harlem

Side sleeping seen as an acceptable compromise

While generally not preferred, moms see side sleeping as an acceptable option. They describe this as a compromise position that avoids the discomfort and risk of choking that they attribute to back sleeping and the risk of suffocation that they perceive in stomach sleeping. Often times moms feel side sleeping allows them to balance the concerns of the doctors (who tell them that stomach sleeping is high risk) with the concerns of their mothers (who tell them that back sleeping is high risk). In order to prop their babies on their sides, moms mention using pillows or wedges in the crib and/or bassinet for support.

Other key attitudes and behaviors

When questioned, moms say they would never put many stuffed animals in a crib, most say they use only one blanket, and about half say it's important to have a firm mattress. Moms do not raise these issues as SIDS risk prevention methods; rather they feel they are common sense.

Moms generally say they wouldn't smoke around the sleeping baby. However, a small number of moms did admit to smoking around the baby on occasions when she felt she had nowhere else to go. Two moms also admitted that they or the father of their baby smoke marijuana around the infant.

Dads

In general, the dads are not as actively or primarily involved with the baby's sleep as the moms. Because many are working and/or not living with the new infant, dads have opinions about how a baby should sleep but in general they do not as actively participate in putting the baby to sleep.

From the sample of research respondents, attitudes towards sleep seem to parallel levels of education. Dads with fewer years of formal education express greater skepticism

toward doctors and a greater reliance on their own intuition and their own mother's experience. However, some of the dads do feel strongly that it is important to trust a doctor's advice.

In general, dads describe recurring conflicts with their "baby mom" over what is best for the baby regarding sleep and other child-care issues.

"I'm a doctor guy. If there is something wrong I want to go to the doctor. But she's like a know it all and she's like, let's wait and see."
– Dad in Brooklyn

Like nearly all moms, the great majority of dads fervently agree that smoking around a baby is bad.

"Its like an unwritten law that smoking should just not happen by the baby."
– Dad in Brooklyn

Caregivers

Caregivers express passionate concern that a baby can fatally choke if it sleeps on its back. In general, caregivers say they prefer to put a baby on its stomach because they believe a baby will typically sleep most comfortably and soundly in that position. Many recount that when they had babies, they were told in the hospital to put their babies on their sides to avoid choking. They still believe that if a person is concerned about a baby's safety, side sleeping is a viable alternative.

"I know from experience that my first son would never have slept on his back, because he had congestion. So I put him on his side – out of fear."
– Caregiver in Harlem

Caregivers believe that their vigilant watching, checking and constant monitoring of babies keeps bad things from happening to them. In this way, they are able to dismiss many preventative safety concerns as unnecessary and not applicable to them.

"You have to know your baby and watch him. That is the best way."
– Caregiver in Brooklyn

Overall, caregivers were emphatic that one should never smoke around a baby, citing research that smoking and second hand smoke is not good for people.

"If it is not good for me, it can't be good for the baby." – Caregiver in Brooklyn

IV – SIDS Awareness and Prevention

SIDS is confusing (and abstract)

Almost all respondents have heard of both SIDS and "crib death" although there is a slightly higher recognition of the latter term. During the discussions, some participants debated whether these were the same, or different – and many feel that crib death is sleep related, while SIDS can happen anywhere and is not confined to cribs or sleep. The majority of participants say that SIDS is something that could strike any baby, at any time.

> *"When death comes, it just comes. There's no way to control it."*
> *– Dad in Harlem*

In general, SIDS ranks as one of many concerns that moms and caregivers have – but one that is less top of mind than more immediate and concrete concerns such as the baby's daily "health" (i.e., is the baby sick?), the baby's comfort, financial issues, and the stresses of being a parent.

Compared to young mothers and even caregivers, young fathers demonstrate a very wide range in SIDS awareness that seems to correspond closely with the father's level of engagement in child rearing. However, one father in Harlem who lived separate from his child and was relatively unengaged was deeply aware of the risks of stomach sleeping because he had lost a baby brother to suffocation.

There is some recognition that the causes of SIDS are unknown, even though many respondents cite suffocation, choking, or overheating as causes. But many respondents also blame the general standard of living in poor urban areas or "the ghetto" as the cause for many of their families' ailments – including mysterious ailments like SIDS. They cite inadequate health care, poor air quality, increased asthma rates, and poor heating as contributors to many of their overall health problems and health risks.

Most parents and caregivers say that their child will not die from SIDS. They believe that they are watchful, loving parents and they have faith that their child will be safe and healthy. Caregivers in particular stress that their constant checking/supervision of the baby is the best prevention for SIDS.

Back sleeping as safe: concept known but not embraced

Most respondents know the SIDS messages, particularly the idea that a baby should sleep on its back. This is particularly true with the young moms, who had received SIDS lectures in the hospital and had seen the nurses put their babies on their backs. Moms also received pamphlets in the hospital emphasizing this message.

Because of the recent hospital education, about half of the moms are aware of the "Back to Sleep" language. Caregivers and dads are, overall, not familiar with that phrase.

However, it is important to note that while the idea (if not the specific language) of "Back to Sleep" has reached this audience, most respondents are 1) skeptical of the idea and 2) not incorporating back sleeping into their practices.

Other SIDS risk factors

As mentioned above, respondents know to avoid much of the other SIDS risk factors, including: over-stuffed bedding (including stuffed animals), smoking around the baby, a soft mattress, and too many blankets in the crib. However, respondents say it is "common sense" to keep the baby safe in these ways. They do not typically state that concern about SIDS is the reason to avoid these actions, but rather that these are important precautions to take against suffocation.

"Nothing in the crib, they might smother." – Mom in Harlem

V – Sleep and Health Information Sources

Regarding sources of information on infants' sleep and health, moms, dads and caregivers say that they trust their own instinct and experience above all else. Second, they cite family members (in particular, their mothers who have had and cared for several babies) as trustworthy sources. Doctors and the medical establishment in general are seen as necessary resources, but ones that are less practical, less accessible, and less trusted than their mothers for most issues. Finally, many respondents also say they trust and use various media sources as an additional resource. Very few respondents mentioned churches or other community groups as a resource specifically for childcare information, but several described these as valued social forums for sharing experiences and knowledge with their peers.

#1 Trusted Source:

Instinct and life experience

Respondents stress that it is important to trust one's own instinct, "common sense" and life experience when determining how best to care for a new baby. Respondents say that finding out what works best for an individual baby always trumps what they might be told.

"If people give me advice, but it doesn't feel right, I'll just do what I think." – Mom in Harlem

"I go by the heart, by mothering instinct." – Caregiver in Harlem

"When my cousin calls me up for advice, there's one thing I tell her – there's no book out there that can tell you what to do. You have to go with your own instincts." – Caregiver in Brooklyn

Moms in particular relate how they feel that they are raising a child amidst "public scrutiny" and are frustrated by institutions and people "telling them what to do." As young black moms in lower income neighborhoods, they feel that the health care community studies them and tries to reform them, and they bristle against this. These perceptions lead to a general skepticism toward more established medical professionals and their advice. It also increases moms' reliance on their own instinct and advice from family members.

"We are manipulated and studied. We're tired of being worked on by society." – Mom in Brooklyn

"I'm sick of people telling me what to do." – Mom in Harlem

Dads communicate a similar perspective. They desire to be respected and to be allowed to make their own choices, as opposed to following the orders or advice of others – and, in general, they strongly resent information or advice that feels like a directive or an order.

"As men, once we have kids, don't tell me what to do with mine. Like, 'Son, you should do this.' I don't want to hear it." – Dad in Harlem

#2 Trusted Source:
Family (older moms primarily)
When instinct is not enough, moms and dads say that they turn to their own mothers, elder siblings, or other family members (caregivers) as their next most trusted resource. These family members are trusted for a number of reasons.

First, caregivers are trusted because they have had extensive experience with babies. Most have had many of their own children, and have raised others besides their own. This experience is highly valued.

"You can call the baby's doctor… but Mom, she is always first." – Dad in Brooklyn

Second, moms say that their own moms are not judgmental. This is crucial in a context where moms feel that they are constantly judged.

Third, caregivers or grandmothers are a logistically feasible resource. As opposed to doctors, they don't charge any money for their knowledge and help, and there is no trip to the clinic or waiting in long lines to see them. Moreover, unlike the doctor, caregivers intimately know the infant in question, and understand the culture and life's realities of the parents.

"My baby is never sick at a timely hour. It's not like I can just run to the doctor. But I can call my Mom." – Mom in Harlem

Another important advantage is that family caregivers are a pro-active resource. For example, moms and dads relay stories of the grandmother going out to the drug store and purchasing items for the baby.

Finally, caregivers enjoy being a valuable resource. This is a role that caregivers themselves say gives them a great deal of pride.

"She (caregiver) knows and loves my baby." – Dad in Harlem

#3 Trusted Source:
Doctors/medical establishment
Most respondents are skeptical of doctors' advice but see doctors and medical professionals as a necessary resource.

"We need them for the baby's shots." – Mom in Harlem

Respondents often discount doctors' opinions because 1) many respondents have had negative experiences with medical professionals (misdiagnoses, and a general lack of respect from doctors), and 2) many respondents feel that most doctors don't have children of their own. In addition, visits to the doctor typically involve long waits, expenses, and bureaucratic or logistical challenges.

"The doctor is a man. He's never had a baby so how can he know."
– Mom in Brooklyn

Parents typically say that beyond the required shots, they take their baby to the doctor only if they are concerned that the problem is serious, and if their own mother or other family members have been exhausted as resources.

"I go to the doctor when nobody else knows what to do." – Mom in Harlem

"You go to the doctor if it's something Mom has never seen before."
– Dad in Brooklyn

Some dads say that doctors, like caregivers, can play the role of tiebreaker when the dad and the baby's mom disagree on how best to care for the baby – but a few of these dads also relayed stories of siding with the doctor just to spite the mother.

#4 Trusted Source:
Media: magazines/brochures/TV/Internet
Media and written resources are mentioned as a lesser-used resource. Respondents do say they have learned about infant care from watching television, and they cite both Oprah and Montel Williams as TV personalities that they trust. Dads say they are drawn to any TV content that relates to young children.

"I'll be flipping through (the channels) and there will be a baby and I'll be like, hold up." – Dad in Brooklyn

Moms mention having looked at some brochures. They say they take all the relevant brochures from the doctor's office, but often most of these go un-read. Some dads say they pick up and read brochures only when they are stuck in a waiting room or a similar situation, where they are bored and need something to read to pass the time.

"I have stacks of those brochures around my room. I never read them." – Mom in Brooklyn

Moms, dads, and caregivers do mention books as resources, but none offered examples of specific advice from books that they trusted and incorporated into their lives.

Respondents also say they sometimes read posters, or watch information on a monitor, if it comes into their awareness – such as on the subway or in a doctor's office.

While a few moms mentioned looking on the Internet for health information, overall, this is not an audience that seeks out information in books or other print or electronic media.

VI – Reactions to Brochure

Reactions and responses to the "Back to Sleep" brochure were very consistent across respondent groups.

Brochure perceived by most as inappropriately targeted to a black audience
A large number of respondents said that the information in the brochure stating that "African American babies are twice as likely to die from SIDS as white babies" made them feel attacked and defensive.

"They figure out why white babies are dying but not African American babies." – Mom in Harlem

"You can't single out the blacks. There are poor whites too. It doesn't matter what the race of the child is." – Mom in Brooklyn

Many said the information contributed to negative stereotypes about African Americans.

"Other kinds of people get SIDS too. It should talk about that, too." – Mom in Harlem

Many were clearly confused by the statistic.

"Why are more black babies dying when there are more white babies?" – Mom in Brooklyn

"When you say that African American babies die more often are you saying that because African Americans have more babies?" – Dad in Harlem

Overall, the statistic alienated respondents and contributed to an antagonistic and skeptical relationship that most respondents felt to the brochure. Most respondents viewed the brochure as coming from a white, book learning, formal, and outsider knowledge base.

"I want to know as a parent, where did they get that statistic?" – Caregiver in Brooklyn

"We need concrete proof on statistics." – Caregiver in Harlem

<u>SIDS ambiguity undermines credibility</u>

Most respondents were drawn to talking about the information that SIDS does not have a known cause. This ambiguity was confusing and undermined the credibility of the SIDS prevention messages. In particular, it provided respondents with a reason to question the "Back to Sleep" messages that were in conflict with what most believed and practiced.

"It says right here they don't know what causes it." – Mom in Brooklyn

"I don't see anything about research being done to find the cause of it … it's only speculation." – Caregiver in Brooklyn

"They don't even know what causes SIDS, but they say, do this, do that." – Mom in Harlem

<u>Choking information dismissed</u>

A considerable number of respondents refused to believe the brochure's claim that infants will not choke sleeping on their backs.

"If the baby's on its back and there's milk left in its mouth you can't tell me that baby's not gonna choke. And if you are sleeping, who's gonna save that baby?" – Caregiver in Brooklyn

"This statement is so incorrect it's ridiculous." – Caregiver in Brooklyn

But many like "the facts"
Despite the alienating race information and the ambiguous SIDS information, several members of each group asked if they could take the brochure home and said they were always glad to have more "facts" on how best to care for their children.

Mixed reactions to the images
There was some concern that the parental images on the brochure were too old. Dads in particular felt that the brochure pictured people who were older and less urban or "hip" than they are.

"They need someone who looks like inner city youth, cause you go to what you know." – Dad in Brooklyn

Some dads said that, given the gravity of a baby dying from SIDS, less happy looking images might scare people like them into actually reading the brochure.

"If I saw a mini coffin (on the cover of the brochure) I would be scared and I would pick it up. I'd say what the hell is this?" – Dad in Brooklyn

A number of caregivers felt that the information in the brochure would be best suited for a younger, less experienced audience and suggested that this audience should be reflected in the choice of images.

Brochure did not convince that "Back to Sleep" is best
Overall, respondents were not convinced after looking at the brochure that they should place a sleeping infant on its back. The alienating race statistic and ambiguous SIDS information allowed the moms and caregivers in particular to hold onto their pre-existing and time-tested beliefs and practices.

"They just don't know my baby." – Mom in Brooklyn

The majority of caregivers, in particular, were generally skeptical of the information and felt that they needed proof that the information was fairly researched and updated. Many spoke of previous crib death information campaigns and expressed an interest in knowing what had been learned in the past 20-30 years. They expressed a mistrust of a seemingly ever-changing campaign, and feel that it is best to stick to what they know – which, for most, was drawn from their own life experience.

VII – Preferred Methods of Outreach

Respondents suggested varying methods of outreach for the creation of a successful campaign.

Moms

Moms, in particular, expressed interest in peer support. All of the young women who participated in the focus groups were fully engaged in the discussions, and at the end of the session expressed an eagerness to stay and talk more. They enjoyed the process of sharing and learning from their peers.

"Can we do this again next week?" – Mom in Harlem

"Is it over already? I want to stay and keep talking." – Mom in Brooklyn

These moms felt that parenting groups and peer discussion groups would be an effective and enjoyable way to learn about each other's experiences. The isolation of parenting and the overwhelming responsibility of caring for an infant create a hunger for peer interaction and new information that they are not getting from other sources.

"I have all the pamphlets and papers from the doctor. I just don't read them … I want to talk to somebody." – Mom in Brooklyn

Dads

Dads also expressed an interest in peer support, but characterized this more in terms of interacting in their local space, with other members of their immediate community. Dads feel that in order to reach young fathers the campaign needs to address them where they hang out and socialize.

" See the moms go to the doctor but a lot of fathers don't. I'd put it where the young people go: the train stations, bus stops, lobbies of the projects." – Dad in Brooklyn

Additionally, dads felt it was important that if the information is directed at them, then it should be delivered by someone from their own community.

"You gotta get people who look like a dude in the street. If a cool looking dude gave it (a brochure) to you, you might take it." – Dad in Brooklyn

Caregivers

Caregivers expressed pride and satisfaction in being "experts" on infant care. Similar to the moms and dads, they enjoyed the group discussions and were interested and engaged with their peers' experiences and opinions. A few suggested that as a part of an

information campaign, they should be officially recognized as experts and their knowledge and understanding utilized as a means of informing others.

"They should use us." – Caregiver in Harlem

While life experience and peer interaction were cited as the most effective ways of learning, many caregivers also spoke of learning about infant care issues via print and other media. They mentioned parenting magazines and pamphlets they had picked up at places that were part of their daily routines, as well as television programs, as other viable ways to reach their population.

"I don't go looking for it, but I have picked up some good information from those magazines at my grandson's school." – Caregiver in Harlem

"There is some very informative information on the TV." – Caregiver in Brooklyn

Summary and Conclusions

The following key conclusions were drawn based on the results of the six focus group discussions.

Mothers and caregivers are the most actively involved in sleep practices
The focus group discussions indicated clearly that young mothers and caregivers are the individuals most intimately and routinely engaged in the decisions and practices regarding the infants' sleep.

Young fathers are typically far less engaged in the infant's sleep practices than either mothers or caregivers. In some cases this is simply due to their separate residence away from the baby and the mother – but even live-in fathers tend to be less engaged, very often due to their work responsibilities outside of the home. These young fathers do generally feel a deep sense of overall commitment and responsibility, but they describe this mostly in terms of loving their baby, desiring to be there as a protector and a role model, and meeting the new financial responsibilities of fatherhood.

Caregivers are key influencers
Caregivers are deeply influential on the mother's practices – even when the caregiver is not the primary individual responsible for putting the baby to sleep. Young mothers seek the advice of caregivers (most commonly their own mother) on a wide range of childcare issues, including the best ways to ensure sound sleep *and* safe sleep. Very often a caregiver's advice will encourage young mothers to engage in sleep practices that are different than what they had learned in the hospital after delivery. Moreover, caregivers feel that their advisory role is important for young mothers and for the baby's health. For this reason, many caregivers expressed interest in being active participants in future SIDS awareness campaigns.

Young fathers do not play a deeply influential role. This does not mean that all young fathers are isolated from the decision-making process or the actual practice of putting the baby down to sleep, but even those fathers who do live in the same household with the baby, and are engaged in childcare, most commonly defer to the advice of caregivers (or, as a second resort, doctors) when it comes to sleep and other childcare issues. In addition, young fathers and young mothers both describe disagreements over childcare issues as a source of tension in their co-parenting relationship. In practical terms, these disagreements are normally resolved by the influence of a caregiver or by the default practices of the person most engaged in the baby's care (the mother and/or the caregiver).

Skepticism toward medical establishment
Moms, dads and caregivers all express degrees of skepticism and mistrust toward the medical establishment. Moms describe feeling that they are raising a child amidst "public scrutiny," and they feel that the health care community studies them and tries to reform them. Both moms and dads express frustration with institutions and people "telling them what to do" – and dads in particular express resentment toward information

that feels like a directive or an order. All respondents, including caregivers, also tend to view the medical establishment as cold and impersonal. These perceptions lead to a general skepticism toward more established medical professionals and their advice, and it increases reliance on their own instinct, experience, and advice from family members.

These skeptical attitudes are underscored by respondents' reactions to the African American targeting in the SIDS brochure (especially the statistic stating how African American babies are at a higher risk for SIDS). For most, this was perceived as yet another example of the medical establishment scrutinizing their community, disregarding their own knowledge or ability, and telling them what to do.

Definition of SIDS unclear, and perceived by many as a product of child's environment
In general, moms, dads and caregivers express a lack of clarity about what SIDS is, how it happens, who it happens to, and why. Many also recognize that the causes of SIDS are unknown. Most respondents implicate suffocation, choking, or overheating (or "over-bundling") as causes. More generally, however, they feel that the likelihood of mysterious ailments such as SIDS is attributable to inattentive parenting, and less advantageous environmental factors in lower-income neighborhoods – including poor air quality, poor heating and housing conditions, and inadequate access to health care.

SIDS awareness is high – but SIDS is not a primary behavior motivator
Awareness of SIDS is high, but the lack of clarity concerning what SIDS is contributes to uncertainty about prevention. This is even the case for young mothers, who have learned about SIDS in the hospital.

Interestingly, most of the behavioral standards for SIDS prevention have been absorbed by the majority of participants, but very few describe these standards as specifically related to a concern about SIDS. Nearly all respondent groups say they avoid keeping stuffed animals and highly stuffed blankets in the crib when the baby is sleeping or unattended. Moms who have a crib know to use a firm mattress. And all respondents say that it is bad to smoke around a baby (as one father said, not smoking around a baby is equivalent to "a law"). But respondents describe these behaviors in terms of common sense, maintaining a healthy environment, and a concern about suffocation or overheating, rather than specifically SIDS prevention.

The only SIDS prevention behaviors that do not seem to be getting through are those that are specific to sleep position and co-sleeping. Young mothers, in particular, have heard that back sleeping is supposed to be the most safe, but the sleep practices they learn in the hospital or through other institutional sources are commonly altered within the first few weeks after the mother returns home with the infant. A number of factors can account for this, including the influence of caregivers, fears that an infant will choke if left on its back, and feelings that back sleeping is uncomfortable or "just doesn't work for my baby." For these latter reasons, a very large number of young parents and caregivers advocate stomach sleeping because they feel it reduces the risk of choking and makes the baby feel secure.

Side sleeping is seen as an acceptable compromise position

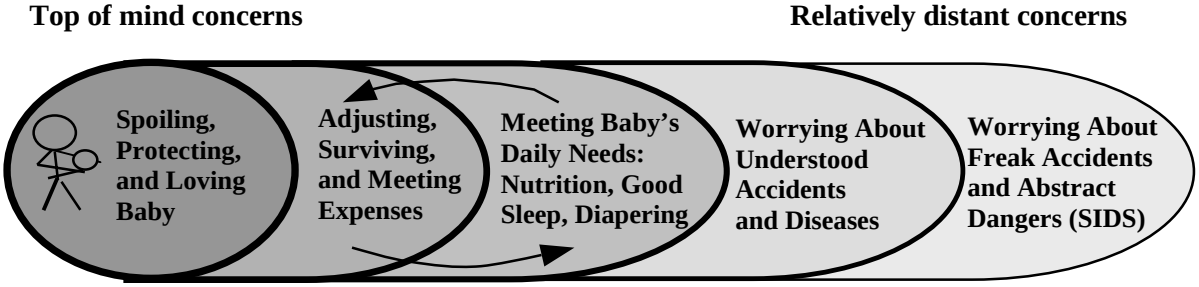
Though stomach sleeping remains a popular choice as the surest way to make a baby physically and psychologically comfortable, side sleeping is widely seen as the safest sleep alternative to stomach sleeping. Participants describe this as a compromise position that avoids the discomfort and risk of choking that they attribute to back sleeping and the risk of suffocation that they perceive in stomach sleeping. Many caregivers also describe side sleep as what they learned when they were parents as the best way to guard against "crib death."

Co-sleeping also viewed as safe – and is valued for closeness

Co-sleeping is viewed as a practice that has many advantages. Closeness to an infant is highly valued because it is felt to provide tremendous psychological comfort to both the child and the adult, while also allowing the parent(s) or caregiver to keep a watchful eye on the baby and to monitor its breathing. In this way, co-sleeping is not only highly valued emotionally, it is also viewed as prevention for many health concerns.

For most, SIDS is not a daily, top of mind concern

The results of the six focus group discussions reveal that young parents are greatly absorbed in the immediacies of their changing roles and responsibilities as new parents. Accordingly, their top of mind concerns are those that are most emotional, pressing, and practical. Caregivers also express that their top of mind concerns are focused on the immediate and practical aspects of day-to-day childcare. As depicted in the diagram below, these concerns are far more present in the minds of the participants on a daily basis when compared to random and unanticipated crises such as childhood diseases, freak accidents, or abstract dangers. SIDS, which is poorly understood and viewed as highly unlikely, is a distant concern.



Top of mind – "spoiling" and protecting: Far more top of mind is the day in/day out experience of loving, "spoiling," and protecting the new infant. With regard to sleep, this desire to spoil and protect means finding the position that seems to be safe but that also offers the greatest possible comfort. Concerns about protection *are* very central for parents and caregivers – but, in general, participants describe the day-to-day job of protecting their infant in terms of preventing its exposure to the risks that they best understand. These include falling, smoke inhalation, choking and suffocation – but not specifically SIDS. SIDS, by comparison, is perceived by the majority of participants as a distant possibility rather than an immediate concern. Some participants view it as a rare

freak occurrence – one that strikes randomly without regard for prevention measures. Others view it as something that happens to babies that are sickly or irresponsibly cared for. In either case, parents and caregivers feel that the odds of SIDS affecting their own baby are very slim.

Also top of mind – adjusting and meeting daily needs: The next most immediate and top of mind concerns for young parents and caregivers are the practical realities of simply getting by and seeing to the baby's – as well as the adults' – day-to-day needs. Young parents worry about their baby's nutrition, health and sound sleep on a day-to-day basis, and good sleep is considered an important foundation for health and development. At the same time, young parents are also worried about their own ability to meet the expenses and responsibilities of being a parent, to adjust to their new lives, and to survive through to the next day. In this context, practices that result in *sound* sleep (stomach sleeping, side sleeping, or co-sleeping) can take precedence over abstract prescriptions for *safe* sleep (back sleeping) – especially when neither mothers nor caregivers are convinced of the comfort or safety of putting a child to sleep on its back. These daily concerns push the specific concern of SIDS further into a distant and less immediate space.

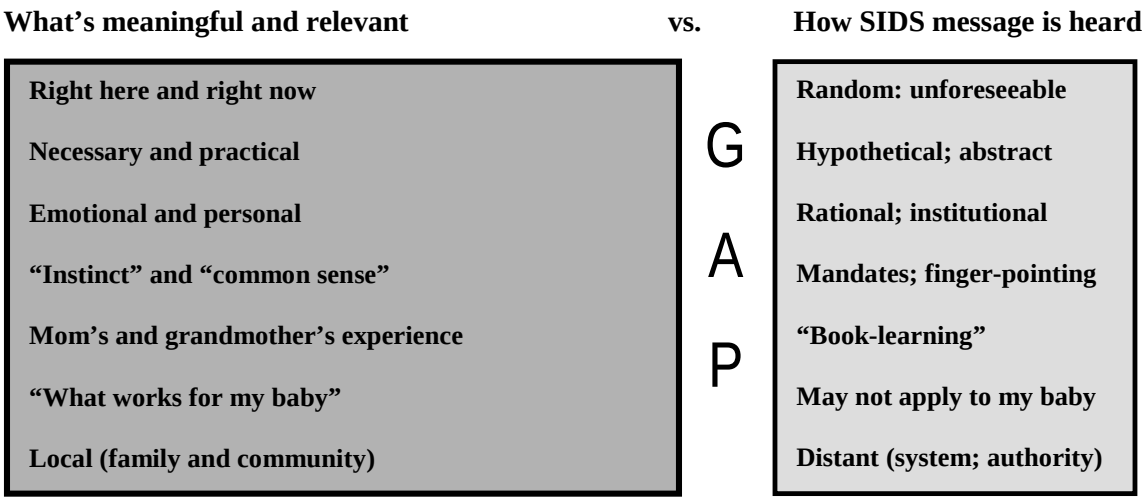
<u>There is a gap between awareness and behavioral change</u>

Although most of the key SIDS prevention messages have reached this audience, the message on sleep position has not been incorporated into behavioral change. Moms definitely <u>know</u>, and dads and caregivers generally know, that health professionals are now recommending that babies sleep on their backs – but this audience does not <u>believe</u> that back sleeping is best for their children. This fundamental gap between awareness and behavioral change reflects a failure of the "Back to Sleep" campaign to resonate with young parents' and caregivers' top of mind, daily emotions and concerns. Where these young parents and caregivers are concerned with issues that are "right here and right now," SIDS is perceived as something that is random, unforeseeable, and distant. Where daily childcare is focused on the necessary and practical, SIDS risk is seen as something hypothetical and abstract. And where engagement with the infant is, at its core, emotional and personal, the "Back to Sleep" prescription is seen as something overly rational, institutional, and impersonal.

The gap between awareness and behavior is further compounded by the distinctive contextual realities in which the participants live their lives. Young parents and caregivers in all groups express skepticism about institutional forms of knowledge and *mandated* practices that seem to disregard their own parenting instincts, their own experiences of parenting, and the knowledge and experience of trusted advisors within their own family or community. As a result, the SIDS message for safe sleep is viewed by many as something distant and overly generalized, not necessarily applicable, disrespectful of their own knowledge and parenting skills – and, at worst, flatly incorrect or accusatory.

This contradiction between what is meaningful and what is heard is represented in the diagram below. The column on the left indicates the most pertinent and valued qualities of daily experience, information and support for childcare. The column on the right

indicates qualities that are felt to be less pertinent and immediate, less trustworthy, less accessible, or alienating.



Implications for SIDS Campaigns

The findings from the focus group research indicate a number of important implications for new SIDS campaigns directed at the populations that these participants represent. We can think of these implications in terms of *audience, content, transmission, and strategy*.

I – Audience: Who to Target and When

Focus on mothers and caregivers

Future campaigns should focus on the mothers and caregivers of infants – that is, those who are most involved in making and influencing decisions and practices related to putting the baby to sleep. Fathers are significantly less engaged in both the decisions and practices of the infants' sleep, and their influence is generally much less significant than that of a caregiver. Moreover, when fathers and mother disagree on childcare issues, these conflicts are very often resolved through the influence of an older caregiver's intervention.

Focus on the point immediately after return from the hospital

The critical opportunity point for influencing behavior is during the first few weeks after the mother returns from the hospital with her baby. This is the time when mothers begin to receive advice and instruction from their own mothers or other family members that might conflict with what they were told in the hospital. It is also the time when young mothers are attempting to adjust to their new life and will eagerly try any advice that helps her baby (and herself) to sleep, as long as she believes it is reasonably safe.

II – Content

Make SIDS less abstract and distant
To the extent that this is possible, clarify what SIDS is and how it can be prevented. Safety issues (falling out of bed, etc.) and health issues (nutrition, good sleep, etc.) are tangible and readily understood – but SIDS remains abstract because it is neither a clear-cut safety issue nor a clear-cut health issue.

Create messages that resonate with the immediate concerns of moms and caregivers
Position SIDS in a manner that treats it as a more relevant, day-to-day concern, comparable to other well-understood risks such as choking and suffocating. Also, address the issue of the baby's comfort and ability to sleep *soundly* as well as *safely*.

Appeal to parenting instincts and common sense
Parents and caregivers do not want to feel that their love or instincts are being questioned, or that they are being told what to do. Pursue content that coaches moms and caregivers along lines that they already feel to be instinctual and correct, rather than mandating behavior that feels foreign and out of touch. To the extent possible, align the message with what caregivers already know and believe, and what they are communicating to young mothers.

Emphasize the personal and the individual, rather than the institutional
Recognize that parents and caregivers are skeptical of "the system" and feel that it does not respond to their needs. De-institutionalize the message by assuring that all babies are individuals and that parents do generally know what's best for their child. Offer options and suggestions for safe sleeping that empower the audience to be the best possible mothers or caregivers without threatening their individuality or autonomy.

Treat sleep position as an issue of its own
Sleep position remains the key issue to address. Other messages about smoking, firm mattresses, blankets, pillows and stuffed toys are getting through and are translating into behavioral change – even if the target audience does not specifically associate these with the prevention of SIDS.

Hit harder on assurances that a baby will not choke when sleeping on its back
Choking is a deeply felt concern, and mothers and caretakers are skeptical of promises that their baby will not choke when sleeping with its head facing upward.

Address the comfort issue
Parents and caregivers need to be assured that their baby is comfortable – psychologically and physically – in whatever sleep position they decide to use. Recognize that a comfortable baby is considered a healthy, happy, well-mothered baby, and that a comfortable baby also gives parents and caregivers a chance to get some sleep for themselves.

Push harder that SIDS can affect *any* baby, but that the risk CAN be greatly reduced
Clarify that SIDS is not limited to infants that are neglected or unloved. Downplay the fact that we do not know what causes it (should this even be mentioned?). Concentrate on the message that we do know how to help protect babies from falling prey.

Simplify the proof and don't racialize it
Hit harder on the proof that safe sleep positioning leads to a dramatic reduction in the incidence of SIDS. Possibly demonstrate this with a simple diagram or bar chart showing the overall rate of incidence in the US *before* the "Back to Sleep" campaign, compared to the overall rate since its inception. Emphasize national, statewide, or citywide statistics, and avoid language or statistics that could be read as "finger-pointing" at a particular racial group or other specific segment of the society.

III – Transmission

Transmit the message as an 'inside job'
Seek out message transmission routes that will be embraced because they are seen as coming from close, community, non-judgmental sources. Sources that are perceived as institutional, distant, or out of touch with a parent's or caregiver's community and lifestyle are more likely to be rejected or treated with suspicion.

Recognize caregivers as the ultimate 'insiders'
Young moms look to caregivers – the infant's grandparents, aunts, godparents and other older, experienced individuals – as trusted and readily accessible sources of childcare information. Caregivers feel that they have valuable knowledge to share, and many of them express interest in being a resource to the community at large. It is important to approach caregivers not only as a target audience for an information and awareness campaign, but also as potential vehicles for broadening the campaign's reach.

Work through trusted community contexts
Partner with preexisting community based programs, frequented social venues, schools or worship communities. These may not necessarily be viewed as childcare information resources by parents and caregivers, but they are important and trusted components of community life and interaction with peer groups.

Work through role models, peers, and respected community members
Work with message bearers that mothers and caregivers respect and view as one of their own. At the local level, these could be peers (other mothers and caregivers), schoolteachers, clergy, or prominent members of the immediate community. Less locally, these could be media personalities who are perceived to be in touch with the concerns and lives of the target group. Participants mentioned, for example, Montel Williams and Oprah as personalities that they trusted and admired.

Encourage transmission through community exchange and dialogue
Expand on the model of the focus groups themselves, which participants described as extremely positive, informative, and enjoyable. Encourage grassroots sharing of parenting knowledge, and find opportunities to use these as vehicles for SIDS education.

Don't assume that people will come looking for information
Unless their concerns require immediate medical attention, mothers and caregivers generally rely on their own experience and the experience of others in the family or community for information and advice. Making information available and accessible is not enough – it must be noticeable and present in their lives.

IV – Strategy

Acknowledge that just raising awareness isn't enough
SIDS awareness is high. The strategic challenges lie in communicating the immediacy and reality of the risk and in modifying behavior, particularly with regard to sleep position.

Consider an incremental campaign to reduce existing barriers to behavioral change
Back sleeping and crib-only sleeping are in conflict with what most caregivers believe, and they contradict what mothers and caregivers feel so intuitively about how to best care for an infant. These emotional and practical positions may not be easy to reverse in the short term. As an alternative to direct contradiction, consider an incremental campaign that ultimately advocates back sleeping but also educates on SAFER co-sleeping and SAFER side sleeping.

Appendix A

ARE YOU A MOM?

$25 for your advice

$25 for your advice

We want to talk to you!

Who We're Looking For…

- ☑ Are you a mother between the ages of 18 and 22?
- ☑ Is your baby under the age of 1?
- ☑ Are you a Black woman (of African-American or Caribbean descent)?

Why You Should Attend Our Focus Group…

- Because we want to learn more about your parenting experiences – so we can create programs for families like yours
- Because you'll get **FREE STUFF**! You'll get $25 cash, a MetroCard, AND food and refreshments.

IF YOU WOULD LIKE TO TAKE PART IN OUR FOCUS GROUPS, GIVE US A CALL!

(212) 442-1756

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Place your baby on his or her stomach for "tummy time" when he or she is awake, and someone is watching. This helps your baby's neck and shoulder muscles get stronger.

For more information on sleep position for babies and reducing the risk of SIDS, contact the *Back to Sleep* campaign at:
1-800-505-CRIB
31 Center Drive, Room 2A32
Bethesda, MD 20892-2425
Fax: (301) 496-7101
Web site: www.nichd.nih.gov

***Back to Sleep* campaign sponsors include:**
National Institute of Child Health and Human Development
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Partners in this outreach include:
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Pampers Parenting Institute • Zeta Phi Beta Sorority

Appendix B

Frequently Asked Questions

Q. *Is there a risk of choking when my baby sleeps on his or her back?*

A. No, babies automatically swallow or cough up fluids. Doctors have found no increase in choking or other problems in babies sleeping on their backs.

Q. *What about side sleeping?*

A. To keep your baby safest when he or she is sleeping, always use the back sleep position rather than the side position. Babies who sleep on their sides can roll onto their stomachs. A baby sleeping on his or her stomach is at greater risk of SIDS.

Some infants may have health conditions that require them to sleep on their stomachs.

If you are unsure about the best sleep position for your baby, be sure to talk to your doctor or nurse.

Some products claim to be designed to keep a baby in one position. These products have not been tested for safety and are NOT recommended.

Q. *Are there times when my baby can be on his or her stomach?*

A. Yes, place your baby on his or her stomach for "tummy time," when he or she is awake and someone is watching. When the baby is awake, tummy time is good because it helps your baby's neck and shoulder muscles get stronger.

Q. *Will my baby get "flat spots" on his or her head from back sleeping?*

A. For the most part, flat spots on the back of the baby's head go away a few months after the baby learns to sit up. Tummy time, when your baby is awake, is one way to reduce flat spots. Another way is to change the direction you place your baby down to sleep. Doing this means the baby is not always sleeping on the same side of his or her head. If you think your baby has a more serious problem, talk to your doctor or nurse.

What Other Things Can I Do to Keep My Baby Healthy?

Get good health care during pregnancy.
- Eat the right foods.
- Do not smoke, take drugs, or drink alcohol while pregnant.
- Get frequent check-ups with your doctor or nurse.

Breastfeed your baby.

Take your baby for scheduled well-baby check-ups.

Make sure your baby gets his or her shots on time.

Enjoy your baby!

Babies Sleep Safest On Their Backs

Reduce the Risk of Sudden Infant Death Syndrome (SIDS)

U.S. Department of Health and Human Services
National Institutes of Health

What is SIDS?

SIDS, stands for Sudden Infant Death Syndrome. It is the sudden and unexplained death of a baby under 1 year of age.

Because many SIDS babies are found in their cribs, some people call SIDS “crib death.” But, cribs do not cause SIDS.

Facts About SIDS

Doctors and nurses do not know what causes SIDS, but they do know:

- ***SIDS is the leading cause of death in babies after 1 month of age.***
- ***Most SIDS deaths happen in babies who are between 2 and 4 months old.***
- ***More SIDS deaths happen in colder months.***
- ***Babies placed to sleep on their stomachs are much more likely to die of SIDS than babies placed on their backs to sleep.***
- ***African American babies are 2 times more likely to die of SIDS than white babies.***

Even though there is no way to know which babies might die of SIDS, there are some things that you can do to make your baby safer.

What Can I Do to Help Lower the Risk of SIDS?

- ***Always place your baby on his or her back to sleep, even for naps.***
  This is the safest sleep position for a healthy baby to reduce the risk of SIDS.

- ***Place your baby on a firm mattress, such as in a safety-approved crib.*****
  Research has shown that placing a baby to sleep on soft mattresses, sofas, sofa cushions, waterbeds, sheepskins, or other soft surfaces can increase the risk of SIDS.

**For more information on crib safety guidelines, call the Consumer Product Safety Commission at 1-800-638-2772 or visit their web site at www.cpsc.gov.

If you use a blanket, place the baby with his or her feet at the foot of the crib. The blanket should reach no higher than the baby’s chest and the ends of the blanket should be tucked under the crib mattress.

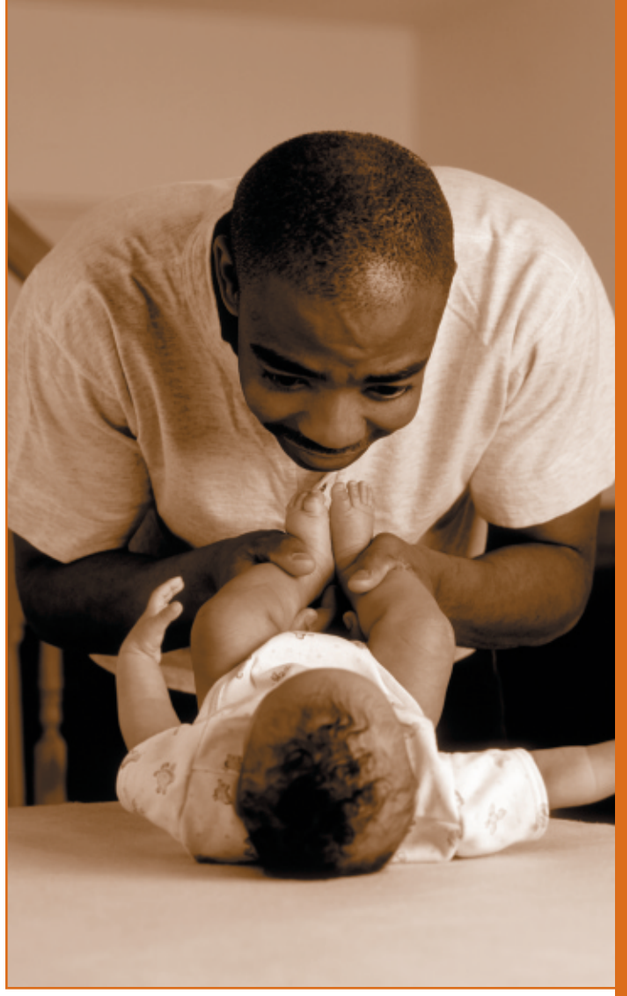
- ***Remove soft, fluffy and loose bedding and stuffed toys from your baby’s sleep area.***
  Make sure you keep all pillows, quilts, stuffed toys, and other soft items away from your baby’s sleep area.

- ***Make sure your baby’s face and head stay uncovered during sleep.***
  Keep blankets and other coverings away from your baby’s mouth and nose. Dressing the baby in sleep clothing will avoid having to use any covering over the baby. If you do use a blanket or another covering, make sure that the baby’s feet are at the bottom of the crib, the blanket is no higher than the baby’s chest, and the blanket is tucked in around the bottom of the crib mattress.

- ***Do not allow smoking around your baby.***
  Don’t smoke before or after the birth of your baby and make sure no one smokes around your baby.

- ***Don’t let your baby get too warm during sleep.***
  Keep your baby warm during sleep, but not too warm. Your baby’s room should be at a temperature that is comfortable for an adult. Too many layers of clothing or blankets can overheat your baby.

- ***Make sure everyone who cares for your baby knows to place your baby on his or her back to sleep.***
  Talk to childcare providers, grandparents, babysitters and all caregivers about SIDS risk.



Babies Should Sleep on Their Backs

One of the easiest ways to lower the risk of SIDS is to put your baby on his or her back to sleep, even for naps. This is new advice. Until a few years ago, doctors told mothers to place babies on their stomachs to sleep. Research now shows that fewer babies die of SIDS when they sleep on their backs.