PARTNERSHIP FOR REDUCING THE RISK OF SIDS IN AFRICAN AMERICAN COMMUNITIES: CASE STUDIES OF THREE SUMMITS

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Executive Summary

Each year, approximately 3,000 infants in the United States die suddenly from inexplicable causes before they reach their first birthday (NICHD, 2000b). These deaths from sudden infant death syndrome (SIDS) have a devastating impact on the affected families. The impact is felt especially in African American communities, where the rate of SIDS deaths is more than twice as high as it is in white communities (NICHD, 2003; DHHS, 2000).

Building on its successful *Back to Sleep* campaign, the National Institute of Child Health and Human Development (NICHD), a component of the National Institutes of Health (NIH), has established a special outreach initiative targeting African American communities with messages about ways to reduce the risk of SIDS. The NICHD has developed partnerships, materials, and activities designed to eliminate the disparity in SIDS rates among African American babies. The communication approach selected by the NICHD is grounded in two theories—the community organization change theory and the diffusion of innovations theory (DHHS, 2002).

One project under this African American outreach initiative is the Partnership for Reducing the Risk of SIDS in African American Communities, a collaborative effort involving the NICHD and three organizations with community-based chapters: the Alpha Kappa Alpha Sorority, Inc. (AKA); the National Coalition of 100 Black Women (NCBW); and Women in NAACP [National Association for the Advancement of Colored People] (WIN). This partnership envisioned, planned, and implemented three regional SIDS summits that provided information and training to more than 1,000 participants, with the goal of ultimately reducing the risk of SIDS in African American communities.

The purpose of this evaluation is to document the complete process of planning and implementing these SIDS summits and to understand the elements that led to the success of the meetings or that served as barriers. The documentation is based on the onsite interviews and summit evaluations completed by participants and on post-summit debriefings held with select participants and planners. The result of the process evaluation is the development and refinement of a partnership logic model that depicts the inputs, strategies, and short-term outcomes of this effort.

A process evaluation model (see page 4) provides an analytic framework to organize observations and document all components of the SIDS summits. The model addresses the context of existing health disparities as well as the environments (missions, leadership, and relationships) of the partner organizations and the NICHD. The model examines elements of the partnership development including the creation of a shared vision and the operational strategies that led to the summits. Finally, the short-term outcomes of the summits, including change in participants' knowledge and attitudes and spin-off events and activities, are documented.

Key evaluation findings include the following:

- The three organizations and their local chapters became involved and enthused about an issue that previously was not a part of their respective agendas, and they were galvanized by the need to reduce the threat that SIDS poses to African American communities.
- Collectively, the partners provided access to a wide range of constituencies that extended their reach to educate and mobilize women, from youth to grandmothers, in SIDS risk reduction efforts.
- Overall, 97 percent of the participants who submitted a reaction form (n = 558) were very satisfied with the summits.

- Most respondents (74 percent) indicated that they were more knowledgeable about SIDS community outreach following the summit.
- The SIDS summits prompted nearly all respondents (98 percent) to consider more specifically what they could do when they returned home, and most indicated that they intended to take some type of next step when they returned to their communities.
- Nearly all respondents (99 percent) found the SIDS summit presenters to be knowledgeable and the materials and presentations clear.
- The *Resource Kit for Reducing the Risk of Sudden Infant Death Syndrome (SIDS) in African American Communities* was well received, and many participants took more than one kit with the intention of ordering more upon their return to their communities.
- Input from each summit helped the partners and other planners to refine the summit process and build on the successes of preceding events. Evaluators also noted that the SIDS summits were not a series of independent events, but rather a process that transcended each meeting, picking up momentum from one event to the next.
- Follow-up activities indicate that the SIDS summits generated other meetings or workshops at the regional and local levels as well as a variety of outreach activities for key audiences, such as parents, health professionals, public health officials, and policymakers.
- As the partner organizations themselves noted, their capability for disseminating health messages has been strengthened and has the potential to help them address other health disparities in the African American community.

Although the process evaluation suggests the initial success of the three summits and partnership development, the report recommends that the NICHD conduct an outcomes evaluation to provide greater details on the long-term effect of these activities. This evaluation would examine the outcomes of government-community collaborations established by the summits and possibly examine whether the summits changed knowledge, attitudes, and behaviors of the participants. Risk reduction can begin to be accomplished through greater understanding and practices to support the *Babies Sleep Safest on Their Backs* campaign. The goal is to eliminate the disparities in SIDS incidence in African American communities.

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Introduction and Background

This report presents observations, insights, and recommendations from an information dissemination process that engaged a partnership of African American women's organizations in supporting the National Institute of Child Health and Human Development's (NICHD) *Back to Sleep* campaign. Using a process evaluation model that describes three summits on reducing the risk of sudden infant death syndrome (SIDS), this report documents how the meetings were planned and implemented, how participants planned to use the knowledge and skills gained at the SIDS summits, how selected participants followed up the summits with actions in their own communities, and how a variety of participants viewed the accomplishments of each event. These findings have been used to develop recommendations for the NICHD on outcome and impact measures that could be used for a subsequent outcome evaluation of the African American outreach component of the campaign.

SIDS AND THE NICHD'S *BACK TO SLEEP* CAMPAIGN

SIDS is the diagnosis given for the sudden, unexplained death of an infant under 1 year of age that remains unexplained after a complete investigation, including autopsy, examination of the death scene, and review of clinical history. In the United States, SIDS is the leading cause of death in infants between 1 month and 1 year of age, accounting for about one-third of all deaths in this age group (NICHD, 1997). Thus, SIDS is a major contributor to infant mortality rates in the United States, which remain among the highest in the industrialized world despite declines since the 1980s. Reducing the rate of deaths from SIDS is a crucial step in reducing the nation's overall infant mortality rate. Consequently, one objective for the national health agenda, called Healthy People 2010, calls for an overall reduction of SIDS deaths from a 1998 baseline of 0.72 deaths per 1,000 live births to 0.25 deaths per 1,000 live births in the year 2010 (DHHS, 2000).

Although the cause of SIDS is still not clear, research suggests several risk factors, including mothers smoking during pregnancy, infant exposure to passive smoke, and premature or low-birth-weight babies (NICHD, 1997). By the early 1990s, the practice of putting infants on their stomachs to sleep was recognized as a significant risk factor for SIDS. Since then, an extensive body of research has shown that placing infants on their backs to sleep reduces their risk of SIDS. In 1992, the American Academy of Pediatrics (AAP) recommended that healthy infants under 1 year of age be placed on their backs or sides to sleep to reduce the risk of SIDS. The NICHD supported additional research to demonstrate that placing infants to sleep on their backs posed no health risks to infants.

Armed with this evidence, the NICHD formed a partnership with national organizations and other federal agencies to launch a public awareness campaign about the importance of placing infants on their backs to sleep. Along with the NICHD, the partnership included the Health Resources and Services Administration's Maternal and Child Health Bureau, the American Academy of Pediatrics (AAP), the Association of SIDS and Infant Mortality Programs (formerly the Association of SIDS Program Professionals), and the SIDS Alliance (now known as First Candle).

In 1994, the NICHD launched the *Back to Sleep* campaign, which reached parents, health professionals, and other caregivers with the message that placing babies on their backs to sleep can reduce the risk of SIDS and save lives. The campaign also recommended other ways to reduce SIDS risk, including not smoking around babies, placing infants on a firm mattress, and removing loose bedding and other objects from the crib. In 1996, the AAP revised the basic recommendation to state that placing babies on their backs is the preferred sleep position and provides the greatest protection against SIDS.

Campaign activities have included conducting a nationwide media campaign, distributing educational materials, maintaining a toll-free telephone line for SIDS education (1-800-505-CRIB), and collaborating with the Consumer Product Safety Commission to issue a safety alert. Since the AAP made its recommendation and the NICHD launched the *Back to Sleep* campaign, the percentage of babies sleeping on their stomachs has declined steadily. This has contributed to a 50-percent reduction in the rate

of SIDS (NICHD, 2003; Centers for Disease Control and Prevention, 1996; Arias et al., 2003). Since the launch of the *Back to Sleep* campaign, SIDS has dropped from being the second leading cause of infant mortality to the third leading cause.

THE AFRICAN AMERICAN OUTREACH COMPONENT OF THE CAMPAIGN

SIDS rates for both African Americans and whites have been cut in half since 1994. However, the disparity between the rates for these two groups remains high—African American babies are still more than twice as likely as white babies to die of SIDS. This disparity is reflected in the disproportionate infant mortality rate among African American infants, which also is more than twice that of white infants (DHHS, 2000). The U.S. Department of Health and Human Services (DHHS) identified infant mortality, which includes SIDS, as one of the six target areas for its initiative to eliminate racial and ethnic disparities in health (Office of Minority Health Resource Center, no date).

A complex combination of factors may contribute to the disparity in SIDS rates. For example, compared to whites, rates of low birth weight and preterm birth are twice as high among African Americans, and these factors increase the risk for SIDS threefold. Certain SIDS risk factors are more common among economically disadvantaged people. It is not clear to what extent factors such as lack of access to health care and inequities in the quality of care, which are more common in minority communities, contribute to disparities in the risk and prevalence of SIDS (NICHD, 2001). Although the *Back to Sleep* campaign has included minority outreach since its inception, studies have found that African American mothers are still nearly twice as likely as white mothers to report putting their infants to sleep on their stomachs (NICHD, 2001).

These findings indicate that the message to put infants on their backs to sleep has not effectively reached the African American community. To improve information dissemination and reduce SIDS rates in this population, the NICHD and other campaign sponsors established a new *Back to Sleep* component that focuses on African Americans. Based on the understanding that to be heard and acted upon, *Back to Sleep* messages must be community-based and culturally sensitive, the Institute invited new partners from the African American community to help develop and implement a community-based approach to eliminating the disparity in SIDS rates.

In September 1999 and April 2000, the NICHD collaborated with the National Black Child Development Institute (NBCDI), campaign sponsors, and other organizations to hold strategy meetings about ways to reach African American communities with *Back to Sleep* messages. Participating organizations included the Alpha Kappa Alpha Sorority, Inc. (AKA), the National Association for the Advancement of Colored People (NAACP), the National Coalition of 100 Black Women (NCBW), the National Medical Association, and the Congress of National Black Churches, Inc. Representatives of these groups provided feedback on ways to effectively address cultural issues and refine campaign messages and materials in light of cultural differences.

As a result of this qualitative research conducted with African Americans, the NICHD determined that the phrase *Back to Sleep* was ambiguous. This research led to a different message to promote back sleeping in African American communities. That message was *Babies Sleep Safest on Their Backs*.

Acting on recommendations from the meetings, the NICHD worked with the NBCDI and other partner organizations to develop culturally appropriate messages and materials to help participating organizations reach African American families and communities. The materials included a resource kit to help organizations initiate SIDS risk reduction activities in the communities served by their local chapters. The *Resource Kit for Reducing the Risk of Sudden Infant Death Syndrome (SIDS) in African American Communities* contains a variety of culturally appropriate materials, including fact sheets, brochures, magnets, a video, and a leader's guide designed to help people lead discussion groups in various community settings.

During National SIDS Awareness Month in October 2000, Dr. David Satcher, the U.S. Surgeon General at that time, unveiled the resource kit and challenged leaders of African American organizations

to join the national outreach initiative. Subsequent collaborative activities included community initiatives in Washington, D.C., and Chicago.

In January 2001, key members of the AKA, the NCBW, and WIN attended an NICHD-sponsored meeting in Atlanta. The meeting included a training workshop on SIDS risk reduction and how to use the resource kit. The consistent presence of the AKA, the NCBW, and WIN throughout the series of planning meetings and at the training workshop fostered the groups' familiarity with each other, the NICHD, and the problems of SIDS in African American communities. During the Atlanta workshop, the three organizations decided to undertake a more collaborative effort to disseminate messages that *Babies Sleep Safest on Their Backs* to their constituents. The subsequent work they did together led to the formation of a partnership and the initiation of a process for planning, implementing, and evaluating a series of regional summits on SIDS risk reduction.

PURPOSE OF THE PROCESS EVALUATION

The purpose of the process evaluation is to document the complete process of planning and implementing these SIDS summits and to understand the elements of the process that led to the success of the meetings (as determined by data-gathering activities following the summits) or that served as barriers to success. The documentation of the planning and implementation of the meetings is based on written communications and reports from summit partners and the NICHD as well as the observations and written documentation of meeting logistics by the primary contractor, IQ Solutions, Inc.

The understanding of the elements that either enhanced these meetings or served as barriers to their success is based on the onsite summit evaluations completed by participants and on post-summit debriefings held with selected participants and planners. The result of the process evaluation is the development and refinement of a partnership model that depicts the inputs, strategies, and short-term outcomes of this effort. Although the model reflects the specifics of the SIDS summits within the African American community, it has the potential to serve as a model for similar efforts to disseminate health messages to the African American community.

EVALUATION METHODS

The process evaluation of the SIDS summits, conducted by the IQ Solutions research division, used a combination of summit feedback/reaction forms and unstructured intercept interviews to gather data from participants and key stakeholders in the summit process. All participants had the opportunity to complete and return the feedback form; however, slightly less than half participated in the evaluation. Nine participants, three from each summit site, participated in follow-up interviews two months after the summit. The nine participants were selected with input from evaluation liaisons representing the partner organizations. Stakeholders, including NICHD staff and leaders of the planning partnership, were interviewed formally after the summits were completed and informally throughout the process (see appendix A).

The information gathered through the meeting reaction forms and intercept interviews with participants and stakeholders provides a descriptive picture of the summit planning and implementation process. However, the data do have limitations. First, the evaluation process began after the partnership was developed and the planning of the summits was well under way. Thus, any data on these aspects of the process were gathered retrospectively from participants in the process. In addition, the response rate to the evaluation form of just less than 50 percent of participants presents the possibility of an existing bias being present in the data. Finally, short-term outcomes are described based on only nine interviews held with participants two months after each of their respective summits.

Appendix A presents a full description of the methods used in the process evaluation as well as the limitations of the study.
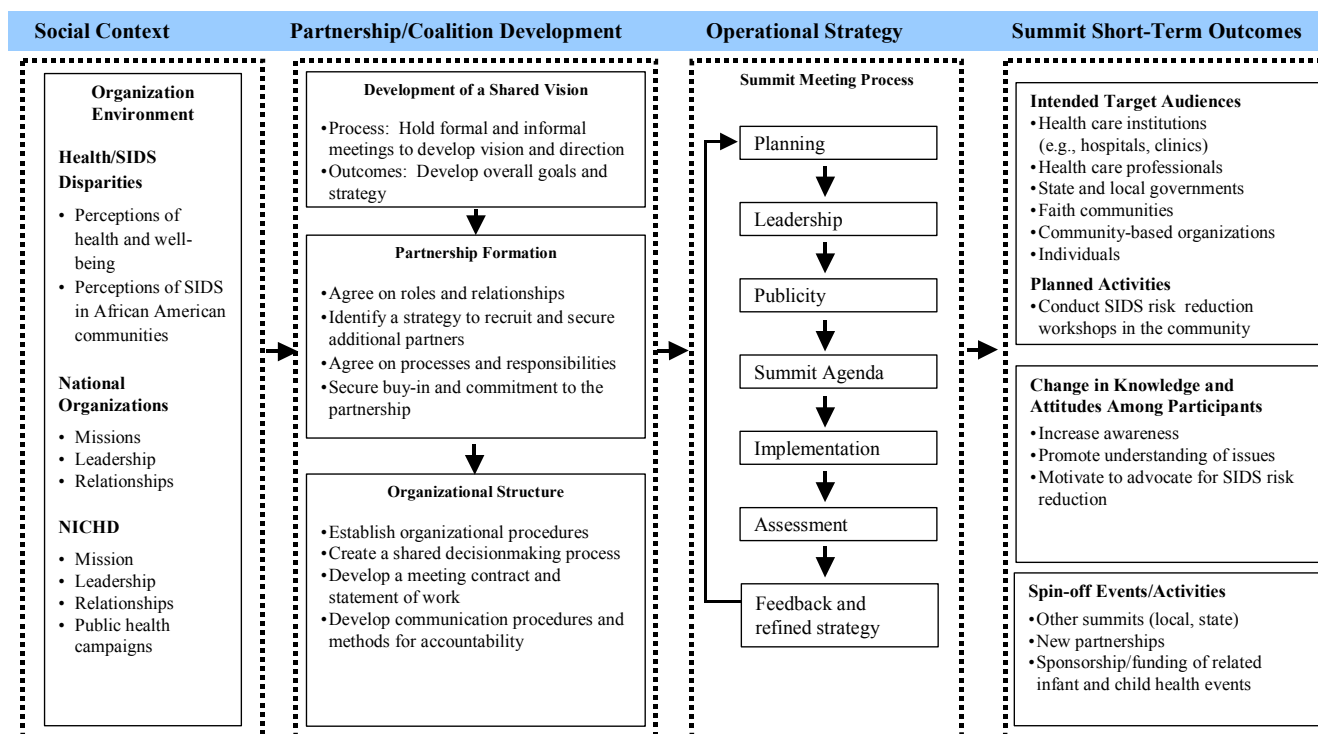
An Approach to Outreach: Partnership Development

A PROCESS EVALUATION MODEL

The success of the initial collaborative training efforts involving the AKA, the NCBW, and WIN led to a new project under the African American outreach component of the *Back to Sleep* campaign. With the NICHD, these three organizations established the Partnership for Reducing the Risk of SIDS in African American Communities. In this partnership, African American women leaders were unified and involved in a national public health initiative with support from members of the medical community, civic organizations, and the federal government. By empowering their local chapters with information and skills, the three partner organizations sought to reduce the risk of SIDS and ultimately to eliminate racial disparities in SIDS rates in African American communities.

The logic model shown in exhibit 1 provides a framework for describing the process through which the partnership was developed and the SIDS summits were planned, implemented, and assessed. The four components of the model represent different stages of the process, with earlier stages feeding sequentially into subsequent stages over time. Each model component, in turn, consists of several key elements that are involved in a particular phase of the process.

EXHIBIT 1
PARTNERSHIP FOR REDUCING THE RISKS OF SIDS IN
AFRICAN AMERICAN COMMUNITIES: A PROCESS EVALUATION MODEL

Social Context	Partnership/Coalition Development	Operational Strategy	Summit Short-Term Outcomes
Organization Environment **Health/SIDS Disparities** • Perceptions of health and well-being • Perceptions of SIDS in African American communities **National Organizations** • Missions • Leadership • Relationships **NICHD** • Mission • Leadership • Relationships • Public health campaigns	**Development of a Shared Vision** • Process: Hold formal and informal meetings to develop vision and direction • Outcomes: Develop overall goals and strategy **Partnership Formation** • Agree on roles and relationships • Identify a strategy to recruit and secure additional partners • Agree on processes and responsibilities • Secure buy-in and commitment to the partnership **Organizational Structure** • Establish organizational procedures • Create a shared decisionmaking process • Develop a meeting contract and statement of work • Develop communication procedures and methods for accountability	**Summit Meeting Process** Planning ↓ Leadership ↓ Publicity ↓ Summit Agenda ↓ Implementation ↓ Assessment ↓ Feedback and refined strategy	**Intended Target Audiences** • Health care institutions (e.g., hospitals, clinics) • Health care professionals • State and local governments • Faith communities • Community-based organizations • Individuals **Planned Activities** • Conduct SIDS risk reduction workshops in the community **Change in Knowledge and Attitudes Among Participants** • Increase awareness • Promote understanding of issues • Motivate to advocate for SIDS risk reduction **Spin-off Events/Activities** • Other summits (local, state) • New partnerships • Sponsorship/funding of related infant and child health events

The model takes into account key elements necessary for the Partnership for Reducing the Risk of SIDS in African American Communities to achieve its goals. First, the effort was established within a social context that included documented racial disparities in African American rates of SIDS and other health conditions. The social context also includes the missions, leadership, and existing relationships among the partner organizations and with the NICHD that were conducive to collaboration. Next, a

shared vision for reducing SIDS risk in African American communities and the subsequent formation of the partnership and its organizational structure fostered partnership/coalition development. Then, the strategies developed during partnership formation were operationalized through the summit process, which included planning, implementation, and assessment. Finally, the short-term outcomes of the summits were documented by feedback collected from summit participants through reaction forms and follow-up interviews with participants and stakeholders.

The value of using a logic model is that it not only graphically presents the flow of the process, but it also illustrates the relationships between key elements of the model and how they interact and influence short- as well as long-term outcomes. The evaluation of the process follows the model, documenting the process from beginning to end. The following discussion presents the information gathered regarding this model's components. After gathering this information, evaluators and key stakeholders can determine if this model needs revision or if it can be replicated with other initiatives.

Social Context

The social context component of the evaluation model documents the environment in which the partnership and SIDS summit activities were developed. Key elements include racial health disparities in infant mortality and SIDS, along with cultural differences in the perception of health and SIDS, and the organizational environments of the three national partner organizations and the NICHD.

Health Disparities

One element of this environment was the disparities in SIDS and infant mortality rates for African Americans, which occur within the broader context of other health disparities experienced by this population. In a presentation at the Los Angeles summit, Dr. Alan Noonan, a Senior Advisor in the Office of the Surgeon General, noted that numerous health disparities contribute to African Americans having among the highest rates of mortality and years of potential life lost among all U.S. racial and ethnic groups (Noonan, 2003).

Within this broader context of racial and ethnic disparities in health are the differences in rates of SIDS and infant mortality, both of which are more than twice as high in African Americans as they are in whites (see Introduction and Background). Continuing disparities in SIDS rates prompted the NICHD to launch the African American outreach component of the *Back to Sleep* campaign and to seek partners with similar commitments to reducing SIDS risk and ultimately eliminating the racial disparity in SIDS rates. As the AKA, the NCBW, and WIN began to participate in the strategy meetings for the outreach initiative, they joined other collaborating organizations in using data on SIDS incidence and prevalence to determine the extent of the problem and its continuing disproportionate effect on African Americans. Thus, over the course of their involvement with the NICHD, these three organizations became better acquainted with the disparities in rates of SIDS and infant mortality and were galvanized by the need to reduce the threat that SIDS poses to African American communities.

Cultural differences in perceptions of SIDS and health and well-being also are part of the social context because they may directly or indirectly influence these disparities and may affect the relevance of and responses to specific messages about approaches to SIDS risk reduction in African American communities. Cultural views also need to be considered when making recommendations regarding the sleep environment for infants.

The Partner Organizations

Another element of the model's first component is the organizational context of the three national partners. Although the AKA, NCBW, and WIN missions did not focus on SIDS prior to becoming involved in the *Back to Sleep* campaign, these organizations share a tradition of sponsoring and

supporting programs to address health and other issues affecting African American women and their communities. For example:

- The AKA has an ongoing focus on alleviating problems concerning girls and women. Health is one of the five program areas targeted in 2002 through 2006. Collaborative activities in the health area address several conditions that affect African Americans disproportionately, including cancer, cardiovascular disease, diabetes, HIV/AIDS, and sickle cell anemia.
- The NCBW implements an array of programs that address problems affecting the lives of African American women and their families, including health issues. The programmatic thrust of the coalition is health, education, and economic empowerment.
- WIN focuses on women and children and encourages its local units to address health and other issues affecting the lives of these target groups. Its general mission includes advocating for the positive development of children. The organization's national theme is "Outstretched Hands and Open Hearts to Women and Children."

Moreover, all three organizations focus on empowering African American women and encouraging their active involvement in service programs in communities across the country. Examples of the focus include the following:

- The AKA comprises college-educated women who have consciously chosen affiliation with the sorority as a way to help improve the socioeconomic conditions in their city, state, and nation, and in the world.
- The NCBW seeks to empower women of color and enable them to make a difference in their communities. The coalition's mission is "the development of socially conscious female leaders who are committed to furthering equity and empowerment for women of color in the society at large, improving the environment of their neighborhoods, rebuilding their communities, and enhancing the quality of public and private resources for the growth and development of disadvantaged youths." The NCBW has established networks among African American women as well as links with the corporate and political sectors.
- WIN offers a means for its members to develop skills in leadership, outreach, and advocacy for empowerment, especially for issues affecting women and children.

A national headquarters with regional and local chapters provides leadership in all three organizations.

- The AKA national leadership includes a president (Supreme Basileus), a national program chair, and a national program committee. At the local level, the sorority has 950 chapters and more than 10,000 members.
- Originally started in the New York metropolitan area, the NCBW became a national organization in 1981. The coalition has a national president and a vice president, 67 chapters, and more than 8,000 members. Each local chapter is driven by a committee structure that initiates and develops concrete programs and activities that respond to the specific character of each community in which the NCBW is based. A sister organization, the NCBW/Community Services Fund, addresses the NCBW's program priorities by designing and developing programs to be carried out by the coalition.
- WIN is an integral unit of the NAACP, and each local NAACP branch may establish a WIN chapter. The organization has a national coordinator, seven regional coordinators, seven state conference chairs, and seven local unit chairs. The national coordinator and the regional coordinators serve as the National WIN Committee.

The core memberships of the three organizations are varied but complementary. They represent three distinct groups of African Americans and, consequently, reach a diverse group of women. As America's oldest sorority established by African American women, the AKA comprises women with collegiate backgrounds, including many members who are professional practitioners. The NCBW's membership consists of civic-minded African American women, most of whom have completed college and hold a professional position. The coalition believes that one of its greatest strengths is the commitment demonstrated by its members, both young and old, which has enabled the NCBW to bridge the generation gap evident in other African American organizations. WIN's status as part of a historical and well-recognized organization—the NAACP—helps to shape its messages and frame its purpose. Through WIN's members, the partnership was able to reach older, middle-class women, often in places where the other two organizations had no affiliations.

Collectively, these memberships provided access to a wide range of constituencies that extended the partnership's reach to the African American population. These three partners provided the *Back to Sleep* campaign with powerful and influential voices for mobilizing other women who wanted to reduce the risk of SIDS. Thus, supporting the *Back to Sleep* campaign—with its aim of saving the lives of infants and reaching women with a simple risk reduction message—fits within key focus areas at all three partner organizations. Moreover, the outreach initiative was in keeping with each group's tradition of actively working in African American communities to effect meaningful change. Finally, the collectively broad range of partner members met the need to educate and mobilize women, from youth to grandmothers, in risk reduction efforts.

The NICHD

The NICHD's history of supporting efforts to reduce infant mortality, eliminate racial disparities, and disseminate information about its research findings to diverse audiences provides the third key element of the social context for the partnership. The Institute's mission is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the opportunity to fulfill their potential for a healthy and productive life, free of disease or disability. This mission encompasses all stages of human development, from preconception to adulthood, and addresses topics related to the health of children, women, and families.

Since the NICHD was established in 1963, reducing infant mortality has been a major focus of its research. In 1974, the Sudden Infant Death Syndrome Act gave the Institute the statutory responsibility to oversee the federal government's SIDS research activities. The NICHD's scientific advances in treating and preventing respiratory distress syndrome, managing the care of premature infants, reducing the risk of SIDS, and enhancing the survival of babies born with birth defects have helped reduce infant mortality by 70 percent in the past 40 years.

The Institute is committed to eliminating racial and ethnic health disparities through its research on conditions for which there are significant differences in health and developmental outcomes, including infant mortality and SIDS (NICHD, 2000a). The goal of this research is to understand the mechanisms by which these differences occur in light of the complex interactions between basic biological processes and factors such as poverty and education. Scientists also seek to identify protective factors, both biological and otherwise, that lead to resiliency and provide the foundation for successfully bridging the gaps in health outcomes.

Throughout its efforts to eliminate health disparities, the NICHD has been mindful of the important role played by community, with its distinct geographic, environmental, and cultural realities. The Institute's strategic plan for SIDS research acknowledged the need for strong community partnerships and knowledge of cultural variations. The communication approach developed by the NICHD and its partners is grounded in two theories. Community organization theory emphasizes the active participation of communities in identifying and addressing their social context and their health needs. The diffusion of innovations theory focuses on the networks, norms, and social structures that influence community-wide change (DHHS, 2002).

A key factor in achieving its mission is the ability of the NICHD to translate and disseminate findings from its research to scientists, doctors, patients, and the general public. To this end, the Institute produces a variety of publications on health topics related to its research and disseminates press releases and other materials to the media.

Within the NICHD's Office of the Director, Deputy Director Yvonne T. Maddox, Ph.D., played a lead role in establishing the African American outreach initiative. She involved the National Black Child Development Institute, which resulted in the SIDS resource kit, and she was involved in all major strategic planning and training meetings since the inception of the initiative, presenting science-based information that provided history and context to the organizations and leaders collaborating with the NICHD. Dr. Maddox also was instrumental in bringing the AKA, the NCBW, and WIN to a shared vision of their potential collective impact on SIDS rates in their communities.

Partnership Development

As relationships developed between the NICHD and the three influential organizations and their leaders, the willingness to collaborate and commit to long-term involvement in SIDS risk reduction efforts grew. Representatives from many organizations attended the Atlanta meeting in January 2001. But three women in particular—Grazell Howard, Esq., Vice President of the NCBW; Norma White, Ph.D., then Supreme Basileus of the AKA; and Thelma Daley, Ph.D., National Coordinator of WIN— shared a desire to get the message that *Babies Sleep Safest on Their Backs* out to even more people. Realizing that as a team they could more effectively reach the African American community, the three women decided to work cooperatively to plan additional SIDS reduction efforts. Subsequent events led to the development of a shared vision, the formation of an informal partnership, and the establishment of a flexible organizational structure. A representative of the CJ Foundation for SIDS also participated in the Atlanta meeting and committed to supporting the effort through grants to these groups.

During the six months following the Atlanta meeting and workshop, the three organizations used their regional meetings to deliver a series of training workshops to more than 1,000 members of their chapters (NICHD, 2003). These women, in turn, trained thousands of local persons in their respective chapters throughout the country. The partner organizations also applied to the CJ Foundation for SIDS to obtain grant funding for their chapters. In October 2001, they secured funding from the foundation for outreach initiatives to reduce the risk of SIDS in African American communities. Through this initiative, 32 grants were provided to local chapters of the partner organizations for the implementation of these activities. The local chapters have received additional funding from the CJ Foundation.

Development of a Shared Vision

Through their joint work on convening the regional training workshops, the AKA, the NCBW, and WIN realized that they could have a greater impact on reducing the rates of SIDS and infant mortality in African American communities if they worked collectively and in collaboration with the NICHD. The shared vision among the three organizations was to reduce the risk of SIDS among African Americans by getting the *Back to Sleep* message out to as many people as possible. The three women who spearheaded SIDS efforts in these groups envisioned an effort to save infants' lives through face-to-face personal contact, for example, with mothers talking to their daughters, daughters talking to their friends, and fathers talking to each other. Such a far-reaching approach could be enacted only at the local level in African American communities across the country. Formal and informal meetings of the organizations' leaders served to articulate and give direction to the idea of extending training and information exchange to more African American women. The idea eventually led to a plan to implement that vision through another series of meetings that would enlist the broad participation of their constituents.

Partnership Formation

As the AKA, the NCBW, WIN, and the NICHD explored the potential of SIDS summits to extend the dissemination of culturally appropriate information and materials on SIDS risk reduction, they entered a period of partnership development. During this phase, the three organizations began to work collectively on their mutual interest in structuring, implementing, and evaluating the impact of the proposed meetings. They took more steps toward developing an informal partnership in which each organization was able to work from its strengths and make unique contributions while adding to a collective knowledge base of experience that grew as the SIDS summit process progressed.

Identify a strategy to recruit and secure additional partners

Although the leadership group did not need to bring in additional partner organizations for the summits, the partners did need to extend the reach of their audiences for future activities. By ensuring that summit participants represented a wide variety of professional and nonprofessional interests—not only members of the three partner organizations—the summit leaders began to recruit potential new collaborators for the future.

After discussing a participant selection process, the partners agreed on inviting a cross-section of individuals. The proposed summit participants included the following:

- Legislators
- Health professionals
- Childcare providers
- Human services personnel
- Clergy and faith-based organizations
- Teenagers/youth
- Participants of Welfare-to-Work programs
- Ethnic media (e.g., radio, magazines)
- Outreach workers
- Senior centers and the AARP

- Key community influencers and informants
- Child protective agencies
- College students
- Families affected by SIDS
- Law enforcement
- Public health departments
- Individuals unique to a geographic locale
- Celebrities
- Academic institutions
- Civic organizations
- Youth organizations (boys and girls clubs)

Secure buy-in and commitment to partnership

Several key factors facilitated the three organizations' buy-in and commitment to the partnership. The impact of SIDS on African American communities was a rallying and motivating influence that galvanized these groups to unite in a common cause. The *Back to Sleep* message was clear and science-based and fit easily within the scope of each of the women's organizations' missions. The fact that culturally sensitive materials were readily available from the NICHD meant that relatively little effort in materials development would be required on the part of the partner organizations. Moreover, the three organizations had provided input for the development of the SIDS resource kit and, as a result, felt a sense of ownership of the kit, which would be featured in training sessions. The NICHD benefited greatly from the partnership.

Through their involvement in strategic planning and materials development, the partner organizations had become familiar with NICHD activities to reduce SIDS risks in African American communities as well as with the Institute's inclusive process that welcomed input and initiative from its partners. As one of the partnership leaders commented, "The trust that the NICHD bestowed on us and its willingness to take a risk was a motivator all by itself." Consultant Stacy Scott, President of In Black Print, provided instrumental on-the-ground liaison support. Ms. Scott has worked on the problem of infant mortality for more than 10 years and specifically with SIDS risk reduction since 1997. With her

previous experience conducting SIDS outreach and education programs in African American communities for the National SIDS and Infant Death Program Support Center, Ms. Scott was able to work closely with the leaders of each organization to help them secure buy-in for the partnership at the organizational (national, regional, and local leadership) and membership levels.

In 2001, the AKA, the NCBW, and WIN pledged to work with the NICHD in getting the *Back to Sleep* message to African American communities. In 2002, the Institute and these three partners agreed to convene three summits in 2003 to generate support for and dissemination of that message. When leadership in the AKA passed from Dr. Norma White to Ms. Linda White in 2002, Ms. White agreed to continue the work of her predecessor, with Ms. Juanita Doty, National Program Chair, leading the AKA's involvement in summit planning. The partners agreed to work as a team and guide every step of the SIDS summit process by supporting one another and facilitating summit development and community outreach throughout the process.

Agree on roles and responsibilities

The AKA, the NCBW, and WIN each agreed to host a SIDS risk reduction summit. The roles and responsibilities of the partner organizations included jointly deciding on the goals, a common format, and an agenda for the SIDS summits. Each host organization was responsible for inviting speakers, preparing workshops, organizing the process for inviting participants, and handling communications for their respective 1-day events.

As the AKA, the NCBW, and WIN worked on the SIDS summits, various messages and ideas began to flow among these organizations and their respective members. Together with highly placed officials in the federal government, the three partner organizations were able to reach more broadly into the African American community to rally constituents interested in SIDS risk reduction.

Organizational Structure

A leadership team was established to guide efforts in communicating SIDS messages to the African American community through a series of events, both nationally and regionally. This team comprised the AKA, the NCBW, WIN, and the NICHD and became known as the Partnership for Reducing the Risk of SIDS in African American Communities.

Establish organizational structures

The partnership created an organizational structure that guided planning and implementation of the summits and helped the partners work in harmony as a leadership team. This structure facilitated shared communication, decisionmaking, and accountability while allowing the flexibility needed by entities with member constituents. An important element of this structure was the involvement of key stakeholders as partners in the process. Each host took lead responsibility for its designated summit and, for the most part, worked separately within its own organization, shouldering much of the responsibility for reaching a full complement of participants at the event. Nevertheless, the three women leaders remained in close communication throughout the process, and the three organizations supported each other in planning and implementing each summit, sharing their mailing lists as well as invitation and participant lists for their respective summits.

Create a shared decisionmaking process

All four partners worked collaboratively throughout the process. All partners shared key information and made decisions collectively. Major decisions regarding the mission and purpose of the summits were made by the group, not by partner organizations acting independently or by the NICHD

acting alone. Crafting roles and scripts for the summits became a group process across organizations. Thus, the anticipated outcome of the summits was celebrated by the entire partnership, not by one organization alone.

Develop a meeting contract and statement of work

The NICHD worked closely with the partner organizations first to understand their needs and then to seek mechanisms to assist the organizations. The Institute issued a Request for Proposals to secure the services of a small business contractor to provide technical and logistical support for the implementation of summit and post-summit activities. The resulting contract provided a mechanism for the partner organizations to receive funds through the federal contractor to pay for labor and other direct expenses, such as the transportation of hundreds of participants to the summit sites.

The primary contractor, IQ Solutions, acted as an intermediary with the partnership, coordinating regular planning and debriefing teleconference meetings with NICHD staff and the partner organizations and working closely with the community partners to help with all advance logistics, including hotel, travel, and meeting arrangements. IQ Solutions assumed onsite conference management and coordination responsibilities at each of the three summits and conducted an evaluation of the SIDS summit process. Delegating the management of conference activities to a professional firm freed the partners from dealing with logistical details and allowed these items to be handled independently of other summit issues. Each partner organization was allotted a specific sum of money to support the summit it sponsored. IQ Solutions monitored the disbursement of these funds, coordinating closely with the NICHD Project Officer and each organization's summit liaison to ensure compliance with federal requirements.

Develop communication procedures

Before the SIDS summits, IQ Solutions and In Black Print facilitated regularly scheduled conference calls involving all members of the partnership. These calls provided updates on the status of logistical arrangements, agenda development, workshop preparation, and participant recruitment for each summit. In addition, ad hoc conference calls were held with the partner organizations, IQ Solutions, and In Black Print when needed to reach an agreement about planning details. The NICHD was apprised of all significant issues and decisions made on official and ad hoc calls.

Operational Strategy

The SIDS summit process, as illustrated in exhibit 1, operationalizes the strategies developed during partnership development. This third component of the model encompasses planning and publicity for the summits, development of a common summit agenda, implementation of the events, assessment of completed summits, and use of feedback to refine the strategy and execution of subsequent events.

Planning

The SIDS summits were more fully envisioned during a Partners Forum held in June 2002 in Florida. This meeting was coordinated for the NICHD by Georgetown University's National Center for Cultural Competency. In developing a unified strategy for the summits, the partners identified goals and objectives for the summits, clarified their respective roles and responsibilities, and created a framework for the summits.

It was decided at the planning forum that although the leaders and members of the partnership would participate in all three summits, each organization would take lead responsibility for organizing and hosting one of the regional meetings to launch its SIDS risk reduction training and outreach activities. The host organization would then continue to serve as the catalyst for activity in that region.

Based on a review of national data on SIDS rates and U.S. Census data, the partnership chose three regions with high rates of SIDS as well as large African American populations. Other considerations were locations where partner chapters and suitable meeting venues were available. The following summit sites, with their respective host organizations, were selected:

- Tuskegee, Alabama (NCBW)
- Los Angeles, California (WIN)
- Detroit, Michigan (AKA)

The partnership also clarified its shared vision and established the following goals for the summits:

- Encourage a significant regional population to engage in SIDS risk reduction activities.
- Build alliances within communities to assist in SIDS risk reduction activities.
- Educate individuals with the power to make a change in policy or behavior.
- Create collaborative models and resources that can remain within communities.
- Encourage participants to conduct additional SIDS risk reduction workshops.

As one of the organizing leaders phrased it, "The SIDS summits would teach African American health professionals and caregivers how to save their most precious and vulnerable resource—their infants."

The proposed framework for the summits was designed to provide members of the organizations and community leaders with educational techniques, strategies, and promotional materials to conduct outreach activities on reducing infants' risk for SIDS in the African American community. This framework was intended to empower participants to lead discussion groups and conduct SIDS awareness programs throughout the year in schools, churches, workplaces, and other settings when they returned to their communities. Although training sessions were an integral part of each summit, partners could decide how to conduct the sessions.

After the decisions made at the Florida forum, the three partner organizations focused on supporting shared interests and purposes for structuring, implementing, and evaluating the impact of the summits. Because each partner wanted to make the meeting it hosted a distinctive success, the summit process emphasized building on the lessons learned from the previous events. As a result, each organization focused on contributing refinements.

Leadership

For each SIDS summit, one of the three partner organizations agreed to take the lead role in organizing the event. However, the other two partners played significant roles in the planning and implementation of all events. They all took responsibility for participant recruitment for each summit and for assisting with the program. As a group, each partner provided feedback following each summit and used the information to revise plans for future summits. Much of the work among these leaders was conducted informally through telephone conference calls held as necessary. Prior to each summit, a conference call was organized to facilitate the final planning of the meeting.

Publicity

The NICHD prepared press releases for each SIDS summit and distributed them with a photo of a baby sleeping on its back to more than 400 African American newspapers, magazines, and radio stations across the country via blackpr.com, an ethnic news release distribution. Each release also was posted on the Web site of the National Newspaper Publishers Association News Service (also known as the Black

Press of America), which is accessed by 200 member newspapers. Media coverage included print, broadcast, and online news. Coverage as of July 29, 2003, is summarized as follows:

Print media impressions	2,403,435
Broadcast media impressions	446,053
Online media impressions	602,000
Total audience impressions	3,451,488

Media outlets carrying the story of the Tuskegee summit included the *Montgomery Advisor* daily newspaper, the Reuters Health news service, two weekly African American newspapers, two African American radio stations, Associated Press Radio, the African American cable television network BET, FOX television, and a local television station. In Los Angeles, summit media coverage included 27 weekly African American newspapers. The story of the Detroit summit was carried by an affiliate of National Public Radio (NPR), an all-news radio station, and Detroit's only community radio station. BlackNews.com covered all three summits, and Detnews.com (a general news site for the *Detroit News* daily newspaper) ran a story on the Detroit summit. Dr. Maddox was interviewed by Blanche Williams for her Greatness by Design show on XM satellite radio after the Detroit summit.

In some cases, the partner organizations used their own or affiliated communication channels to publicize the events. For example, WIN's parent organization, the NAACP, issued an online news release about the Los Angeles summit and provided the name of a contact in the NAACP Office of Communications. The timing of the news releases (usually issued just before or during the events) indicate that the primary role of this publicity was not to affect meeting attendance but rather to call attention to the purpose of the summits and, thus, increase awareness about SIDS and the NICHD's African American outreach initiative.

Limited information is available about the partners' efforts to recruit participants by disseminating information about the upcoming summits to their constituents and other interested individuals in the region. However, a few participants mentioned the need for more effective publicity prior to the events. Participants at all three summits commented on their reaction forms that information about the summit could have been better in terms of either earlier or broader dissemination.

Summit Agendas

Although each SIDS summit was unique, they all had an implicit goal of reducing the risks of SIDS in the African American community. Each event also echoed the SIDS summit theme, "A Journey for Our Children." The structure of the three regional summits sought to provide participants with an opportunity to learn more about SIDS, engage in interactive exchanges with workshop and summit leaders, and receive training in how to use the NICHD's SIDS resource kit. The partners agreed that the summits would not be configured to replicate each other precisely, so that each could reflect the culture of the respective sites and hosting organizations. However, it was decided that the summits would be designed to provide similar information that could be tracked and evaluated for program efficacy over time and within each participating region.

According to this design, the three summits had a common format that included the following components:

- A reception on the evening before the plenary and breakout sessions to welcome participants and facilitate networking—local dignitaries and lead officials of the partner organizations and the NICHD provided introductions to the summit
- An opening session with official greetings and introduction of the partners, special participants, and local officials

- A morning plenary session providing an overview of the current knowledge about SIDS, with supporting national and local data and history, and a question-and-answer period
- A networking lunch session with motivational speakers
- Concurrent afternoon breakout sessions with workshops providing training on SIDS risk reduction messages, message dissemination, and use of the SIDS resource kit (four sessions were geared to health care professionals, caregivers, advocates and policymakers, and community outreach leaders)
- A closing ceremony with a charge to participants, testimonials, and a call to action

Implementation

Each SIDS summit implemented this common format in different ways. Each event varied in the activities conducted, the participants attracted, the information presented, and the logistical arrangements made. Each event also reflected the host organization's strengths. The NCBW's Tuskegee summit offered historical perspectives and reflections from community elders. The Los Angeles summit hosted by the WIN emphasized policy analysis and diverse, intergenerational participation. The AKA's Detroit summit highlighted the involvement and participation of African American professionals, public health organizations, and faith-based leaders.

Activities

Although all summits were consistent in format and organization, each event also incorporated distinct segments intended to reflect the culture of the respective region and the host organization. For example, the first summit, held in Tuskegee, coincided with the beginning of Black History Month celebrations and took place at a university with historic significance for the African American community. In the opening session, Tuskegee's mayor and a prominent civil rights advocate provided a historical context for the SIDS risk reduction effort.

The Los Angeles summit began with a Policy Builders Luncheon for NAACP members and invited guests. Held on the afternoon before the full summit, the luncheon provided an opportunity for community leaders, health department officials, and other key leaders to discuss policy implications of the SIDS summits. Speakers provided information to establish a context for the summit and introduced the broader topic of general health issues and disparities facing the African American community.

The Detroit summit was extended to a third day for a "SIDS Sunday" kickoff event at a local church on June 1, 2003. The activity provided a role for Detroit churches to impart the SIDS message to their congregations. Some 75 AKA members joined approximately 2,000 other people at Detroit's Hartford Memorial Baptist Church, where Dr. Maddox and Rev. Dr. Charles G. Adams spoke about reducing SIDS in African American communities. The director of the health care ministry at Hartford, who had attended the SIDS summit, designed a church bulletin board featuring SIDS and handed out SIDS information to church members. Participants were asked to contact their churches and provide written feedback to the AKA about the outcome of SIDS Sunday events during July 2003.

Other agenda components that were amenable to variations at each site were the reception, opening session, luncheon, and closing ceremonies. These activities gave the host organizations an opportunity to highlight their own involvement and the support of local dignitaries. Receptions varied in their approach to introducing attendees to the next day's activities. At Tuskegee, speakers presented highlights of the SIDS summit's history, goals, and call to action; the two subsequent summits used the receptions more for networking and introducing key individuals. Opening session speakers, who provided inspiration and a context for the work of the summits, included the mayor of Tuskegee and a pioneering civil rights lawyer and advocate (Tuskegee), and Michigan's first state surgeon general (Detroit). Local choirs, school bands, and participants provided music at the receptions, luncheons, and closing ceremonies. Luncheon speakers were drawn from the respective regions and provided additional

information and inspiration. As each summit was documented on videotape, luncheons began to include a showing of inspirational highlights from the preceding events. Closing ceremonies were designed to reinforce the call to action. They included a "Celebration of Life" service and evangelical sermon at the Tuskegee University chapel; a commemorative tribute and ecumenical prayers by leaders from different faiths at the Los Angeles summit; and a meditation, sermon, and memorial tribute with glow lights at the Detroit summit.

The most consistently executed components of the summit agenda were the information-sharing sessions, specifically the introductory presentations by Dr. Maddox, the morning plenary session, and the afternoon breakout sessions. At each summit, the NICHD Deputy Director presented background information on SIDS, the Institute's involvement in SIDS research, the *Back to Sleep* campaign, and the evolution of the African American outreach initiative and the SIDS summits. The morning plenary sessions featured presentations by doctors, public health officials, and representatives of local SIDS programs. All four breakout sessions were conducted at each summit, imparting information on how to use the SIDS resource kit in different settings.

Elements of even these consistent components varied in terms of specific content and approach. Plenary panels highlighted SIDS statistics, public health challenges, and outreach initiatives specific to the participants' regions. Morning speakers introduced different topics, such as broader issues related to racial and ethnic health disparities (Los Angeles and Detroit) and the relationship between health disparities and behaviors such as racism (Los Angeles). Input from preceding summits allowed refinements to better accommodate participants' information needs. As a result, plenary and breakout sessions became more interactive and included more aids, such as slides and handouts.

Integrating factors at all three summits included the presence of key partnership representatives such as Dr. Maddox, Dr. Daley, Ms. Howard, Ms. JoAnn Battle, and Dr. Norma White, as well as their consistent message—*Babies Sleep Safest on Their Backs*. One evaluator's impressions were that participants felt that everyone got the message and that the summit objectives seemed clear enough so that everyone could leave with a plan to personally do something about SIDS.

Exhibit 2 summarizes the schedule of activities at each of the three summits.

EXHIBIT 2
SCHEDULE OF ACTIVITIES AT THE SIDS SUMMITS

	Tuskegee	Los Angeles	Detroit
Reception	7 to 9 p.m. Welcome from the first African American female mayor of the city of Tuskegee. A brief history of the origins of the proposed regional SIDS summits was provided as well as the role of the NICHD. A summary of the summit goals was given with an accompanying demand for participants to play an active role in the following day's planned workshops.	7 to 8:35 p.m. Welcome from a local high school jazz band with Dr. Thelma Daly serving as the emcee. Participants were able to pick up all conference materials at registration tables outside the reception hall. Dr. Daly introduced key members of the national planning committee, the NICHD, and some of the key speakers for the next day's sessions.	7 to 9 p.m. Welcome from Ms. Linda White, National President of the AKA, with accompanying music provided by the Pontiac Northern High School Jazz Band. The national planning committee members were introduced, including the NICHD; JoAnn Battle, chair, Detroit SIDS summit; Kimberlydawn Wisdom, M.D., Michigan Surgeon General; and others.
Plenary	9:30 to 10:30 a.m. Welcome address and remarks. Attorney Dovey Roundtree served as the guest speaker, following the introduction and welcome by the NCBW's Ms. Grazell Howard, Esq. 10:30 a.m. to 12 noon. The plenary included presentations from the NICHD's Dr. Yvonne Maddox and others. A short question-and-answer session was held before the lunch break.	9:15 a.m. to noon. Two separate plenary panels were held.	9:10 a.m. to 12 noon. A question-and-answer session with Dr. Maddox and Dr. Nathan Stinson encouraged interactive discussions with participants on health topics beyond SIDS.

EXHIBIT 2
SCHEDULE OF ACTIVITIES AT THE SIDS SUMMITS (CONTINUED)

	Tuskegee	Los Angeles	Detroit
Luncheon	12 noon to 1 p.m. During a working lunch, participants were tasked with a flexible table discussion topic on what the measurable goals of the summits could be and how they, as individuals and members of the larger community, could effect change.	12 noon to 1:30 p.m. Nothing formal was planned. The luncheon provided an opportunity for participants to network and decompress from the morning plenary. A video of the Tuskegee summit was shown.	12:30 to 1:30 p.m. The video *Reflections from the Tuskegee and Los Angeles Summits* was shown.
Workshops	1 to 3:45 p.m. All four workshops were presented.	1:45 to 3:45 p.m. All four workshops were presented.	2:15 p.m. to 4 p.m. All four workshops were presented.
Celebration of Life	4 to 5 p.m. A sermon was held in the Tuskegee University chapel.	4 to 4:30 p.m. Prayers conducted by an ecumenical minister were followed by open comments from participants.	4:15 to 5 p.m. Prayers led by Rev. Dr. Laura Foster were followed by "glow light" prayers by participants.

Participants

Although the number of participants, states represented, and certain evaluation activities (e.g., participant interviews) varied at each summit site, similar proportions of attendees participated in the workshop sessions (47 to 52 percent) and returned reaction forms (46 to 49 percent) at all summits. Exhibit 3 provides a summary of participation and evaluation activities at the three summits.

	Tuskegee	Los Angeles	Detroit
Date	January 31-February 1, 2003	March 14-15, 2003	May 30-June 1, 2003
Host Organization, with the NICHD	National Coalition of 100 Black Women	Women in NAACP	Alpha Kappa Alpha Sorority
Participants' State of Residence	Alabama, Florida, Georgia, Illinois, Kentucky, Louisiana, Mississippi, Missouri, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Tennessee, Washington, D.C.	Alabama, Arizona, Arkansas, California, Colorado, Georgia, Idaho, Louisiana, Maryland, Michigan, Nevada, New Mexico, North Carolina, Ohio, Oregon, South Dakota, Utah, Washington, Wyoming	California, Florida, Georgia, Illinois, Indiana, Kansas, Michigan, Missouri, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Texas, West Virginia
Number of Participants	457	220	520
Number of Workshop Participants	227 (50%)	114 (52%)	246 (47%)
Number of Reaction Forms Collected	213 (47%)	108 (49%)	237 (46%)
Number of Participant Interviews at Summits	26	33	18
Number of Participant Follow-up Interviews	3	3	3

Among the nearly 1,200 participants, people came from 33 States and the District of Columbia. This included approximately 15 members of the NICHD program staff, the planning committee, and the contractor staff. More than half of the participants at the Los Angeles summit were from California, which is not surprising considering the state's size and population. However, participants from several predominantly rural states with very small African American populations provided geographical diversity

at this summit. This representation led to some unique experiences for rural participants (e.g., a participant who met an African American physician for the first time, a county health nurse who finally found an African American organization in her city). All three summits included men and women as well as people of different generations as participants. However, Los Angeles and Detroit had greater participation by men and by adolescents than did Tuskegee.

Many participants learned of the summits by word of mouth and arrived without preregistering. This last-minute turnout, along with the fact that many registrants sent substitutes without notifying summit organizers, made it difficult for meeting planners to capture full contact information for all attendees. Although not all participants designated their affiliation, available information indicates that members of all three partner organizations attended each summit. Exhibit 4 summarizes the identified partner organization affiliations of summit participants. In two of the three summits, at least 25 percent of all participants did not represent the lead organization at the event. However, affiliations were more likely to reflect the host organization, especially in Detroit, where no onsite registration was conducted.

EXHIBIT 4
PARTNER ORGANIZATION AFFILIATIONS OF SIDS SUMMIT PARTICIPANTS

Summit Participant Affiliation	SIDS Summit Site and Host Organization		
	Tuskegee (NCBW) (n = 457)	Los Angeles (WIN) (n = 220)	Detroit (AKA) (n = 520)
AKA	22 (5%)	12 (6%)	212 (41%)
NCBW	101 (22%)	15* (7%)	14 (3%)
WIN (or NAACP)	11 (2%)	68* (31%)	8 (2%)

* One participant reported affiliation with the AKA and WIN; one participant reported affiliation with the AKA and the NCBW. The numbers listed count these two participants twice to fully indicate affiliations.
Note: A list of all participants with their affiliations is not available.

Backgrounds represented by participants included most of the areas identified at the planning forum, including the following:

- Legislators
- Health care professionals and professional associations
- Hospitals and health clinics
- Childcare providers and associations
- Local SIDS programs, coalitions, support centers, and foundations
- Healthy Start and other infant health programs
- Head Start programs
- Child health insurance programs
- Child development and learning centers
- Shelters for women and children
- Foster parents and foster parents associations
- Outreach workers and human services personnel

- Clergy and faith-based organizations
- Teenagers/youth
- Ethnic media (e.g., radio, magazines, public relations firms)
- Senior centers and organizations
- Community activists
- Child protection and domestic violence agencies
- College students
- SIDS family members
- Public health departments
- Public schools
- Academic institutions
- Civic organizations
- Voluntary health organizations
- Youth organizations (e.g., mentoring programs, student unions)

Information disseminated

The SIDS summits provided the following types of information to support the goals of the NICHD's African American outreach initiative.

Goals and Call to Action. At the opening sessions of the Tuskegee and Los Angeles summits, Dr. Maddox articulated the goals of the summits. At the Tuskegee summit, the NICHD Deputy Director cited the following goals:

- To support the message that *Babies Sleep Safest on Their Backs* and deliver that message to African American communities
- To obtain input from the communities to determine how the campaign can be more responsive and more culturally appropriate for African Americans
- To provide a means for measuring progress, communicating information to communities, and disseminating messages to target audiences

At the Los Angeles summit, Dr. Maddox also related the purpose of looking at ways that people can reduce the risk of SIDS in African American communities. Throughout all three summits, various speakers described the call to action as spreading the message in African American communities.

The NICHD. Speakers at the opening sessions provided background information on the NICHD, the federal sponsor of the summits. The following topics were addressed:

- The NICHD mission
- NICHD research on SIDS
- The *Back to Sleep* campaign
- The evolution of the African American SIDS outreach initiative and the SIDS summits
- The NICHD's culturally appropriate SIDS materials, including the resource kit

SIDS Issues. In the opening and plenary sessions at all three summits, the following information was provided about SIDS and related issues:

- The definition of SIDS
- The possible causes of SIDS
- Disparities in SIDS rates
- SIDS risk factors
- Risk reduction strategies (e.g., put babies on their backs to sleep, avoid smoking around infants, avoid smoking when pregnant, avoid soft bedding and overheating)
- The importance of basing messages on facts, with a focus on *reducing the risk of SIDS* rather than on *eliminating SIDS* (emerged in Los Angeles and repeated in Detroit)
- The importance of support for families affected by SIDS

Information on the following SIDS issues were provided during specific breakout sessions:

- Statistics about SIDS deaths in childcare settings (caregivers)
- Emergency procedures that should be used in the event a child is found unresponsive or dies in a childcare setting (caregivers)
- Considerations that should be addressed in sleep position policy for childcare facilities (caregivers)

- Guidelines for death scene investigations (health professionals)
- Myths that need to be dispelled (different sessions at the three summits)

SIDS Outreach. At each summit, a panel of presenters provided statistics on the local impact of SIDS. Presenters and participants described local initiatives to address these challenges. During the breakout sessions, moderators presented information on ways to use the NICHD's SIDS resource kit effectively. Their presentations, which varied according to the session topic, addressed the following:

- How to use the resource kit's training curricula
- How to establish a sleep position policy in a childcare setting
- Tips for communicating sleep position policy to parents
- How to use the sample legislation provided in the kit in contacting legislators to propose autopsy protocols

Moderators and participants in breakout sessions exchanged ideas on the following topics:

- Avenues for disseminating messages
- Examples of outreach activities
- Target audiences
- Tips for effective outreach
- Barriers to effective outreach

Broader Context of Health Issues in African American Communities. Speakers at the opening, plenary, and luncheon sessions presented information that provided a broader context of health issues in African American communities. Contextual information included the following:

- Overall health disparities in communities of color (Los Angeles and Detroit)
- Disparities in infant mortality in African American communities
- Health disparities in African American women
- Efforts of the DHHS Office of Minority Health to eliminate health disparities (Detroit)
- Behavioral factors (e.g., racism) that contribute to disparities (Los Angeles)

Inspiration and Motivation. All summits included information and activities designed to inspire and motivate participants. Inspirational and motivational elements of the summits included the following:

- A call to action by prominent speakers (e.g., local dignitaries, women ministers, pioneering advocates, federal representatives)
- Videos of previous SIDS summits (Los Angeles and Detroit)
- Prayers, hymns and other inspirational music, sermons, and memorial tributes to infant lives lost to SIDS

Materials. Materials disseminated at the meetings provided additional information. These materials included:

- The SIDS resource kit, including a resource guidebook, training guides, a video, a hanger with the *Back to Sleep* logo and messages, brochures, refrigerator magnets, and a sample bus advertisement

- Handouts from breakout session moderators at the Los Angeles and Detroit summits
- Public health handouts from local agencies that addressed SIDS and other health issues

Logistics

Logistical arrangements for the summits involved booking lodging and meeting facilities; organizing a reception, breakfast, and luncheon; procuring audiovisual equipment and assistance; and facilitating travel, usually by bus, to summit sites.

Inevitable difficulties arose in the arrangement of lodging and sufficient food for last-minute participants who had not preregistered for the summits. Difficulties in accurately predicting the estimated number of attendees led to shortages in available meals and lodging. For example, in Tuskegee, where nearly twice as many people attended as were expected, rooms had to be booked as far away as 40 miles from the meeting.

Assessment

To assess the success of the summits from the perspective of the participants, a reaction form was distributed to all attendees and collected on the last day of each summit. Nearly half of all participants at each summit completed and returned the evaluations: 47 percent (213) in Tuskegee, 49 percent (108) in Los Angeles, and 47 percent (237) in Detroit. In total, 558 reaction forms were collected. The evaluation forms included questions on overall satisfaction with the meeting, clarity, value and utility of the presentations and materials, and knowledge gained from the meeting. The majority of the questions provided a scale (0 to 5) from which to respond, with a few open-ended questions used to probe for some specifics. Exhibit 5 summarizes the average score for all close-ended questions on the participant reaction form.

In addition, informal participant interviews were conducted in each site: 26 in Tuskegee, 33 in Los Angeles, and 18 in Detroit. These interviews were helpful in gaining insight into particular aspects of the summits that were most or least successful and ways that people intended to use SIDS information when then returned to their communities. This section presents the highlights of the findings from these evaluation activities.

Overall perceptions of the summits

The overall perception of the summits was highly favorable, with the vast majority of respondents (all but 15 of 558) rating their satisfaction with the meetings at 4 or 5 (5 being the highest rating of "very satisfied"). The information and SIDS resource kits were viewed as being clear and most helpful. Participants appeared to have learned a lot from the sessions and were clear about how they could use the information from the SIDS summits.

Among respondents who had previously attended another meeting, conference, or workshop on SIDS (N = 56), at least 75 percent rated the NICHD SIDS summits as being more helpful than the previous events (90 percent in Tuskegee, 75 percent in Los Angeles, and 75 percent in Detroit). No respondents rated the event less helpful than a previous event. Although many participants indicated that all summit sessions were helpful, some workshop sessions were more likely than others to be rated as "most helpful."

Change in knowledge

Regarding their knowledge of SIDS, most respondents indicated that they were more knowledgeable after the summit. Most participants (80 percent) who did not indicate a gain in knowledge

had indicated the highest level of prior knowledge on the scale. Among persons who indicated gaining knowledge at the summit, the average gain was approximately two scale points on a five-point scale. (See items 10a and 10b in exhibit 5.)

EXHIBIT 5
AVERAGE RESPONDENT SCORES ON OVERALL SATISFACTION WITH SUMMITS (AS REPORTED ON REACTION FORMS)*

Evaluation Question	Tuskegee N = 213	Los Angeles N = 108	Detroit N = 237	All Sites N = 558
1. How satisfied were you with this summit meeting?	4.72	4.898	4.820	4.813
2. How helpful is the information that was presented?	4.85	4.897	4.881	4.876
3. How helpful were the SIDS resource kits?	4.86	4.980	4.894	4.911
4. How would you rate the conference facilities and services?	4.69	4.859	4.826	4.792
5. Overall, how knowledgeable were the presenters about the topics presented?	4.88	4.935	4.909	4.908
6. How clear and understandable was the information presented?	4.85	4.962	4.892	4.901
7. How clear are you about how to carry out community outreach?	4.76	4.870	4.685	4.772
8. How clear are you about how to use the information you received at this summit meeting?	4.79	4.869	4.751	4.803
9. What is your comfort level regarding how to use the SIDS resource kits?	4.71	4.755	4.612	4.692
10a. How knowledgeable were you about SIDS community outreach before the meeting?	3.26	2.524	2.576	2.787
10b. How knowledgeable are you about SIDS community outreach after the meeting?	4.72	4.728	4.727	4.725
11. How culturally sensitive were the meeting presentations and activities?	4.71	4.761	4.792	4.754

(Total number of respondents = 558)
*The scale ranged from 0 to 5, with 5 being the highest rating of "very satisfied."
It should be noted that the majority of all scores fall between 4 and 5 on the 5-point scale. This makes it very difficult to understand the variation in responses and to interpret the answers of those who were less than satisfied (responses of less than 3).

Plans for community action

Data gathered from the unstructured interviews with participants during the summits indicate that the event's objectives were simple enough that participants could leave with a plan to personally do something about SIDS.

- I have what I need now to do something about SIDS—the words "Put your baby on its back to sleep."
- I don't have to wonder about how to do something. I just need to spread the word—"Put your baby on its back to sleep." Even a child can spread this word.
- Because of my personal experience (lost a nephew to SIDS), I want to spread new, correct information. This conference has given me the tools I need.

Nearly all participants who turned in reaction forms at the three summits indicated that they intended to take some type of next step when they returned to their communities (see exhibit 6). The step that most respondents (65 percent) were most likely to take upon returning to their communities was talking with friends and neighbors about SIDS. Nearly as many respondents anticipated using resource kit materials to give presentations about SIDS (61 percent) or handing out materials from the kit (60 percent). Meeting with community leaders about SIDS was the activity least reported (39 percent). Other activities planned by respondents included:

- Holding trainings or workshops for staff, students, parents, or church members
- Contacting the media, legislators, or medical associations
- Integrating SIDS information into the participant's current activities (e.g., classes in CPR or child development) or publications (e.g., newsletters, church bulletins)
- Conducting outreach to mothers, parents, Healthy Start participants, women's prisons, or health care professionals
- Conducting their own summits or symposia

EXHIBIT 6
INTENDED NEXT-STEP ACTIVITIES REPORTED BY
EVALUATION RESPONDENTS (BY SITE AND FOR ALL SUMMITS)

	Proportion of Respondents in Tuskegee (n = 213)	Proportion of Respondents in Los Angeles (n = 108)	Proportion of Respondents in Detroit (n = 237)	Proportion of All Respondents Across Sites (n = 558)
Use SIDS resource kits for presentations	67%	69%	54%	61%
Hand out kit materials	66%	64%	55%	60%
Talk with friends and neighbors	76%	64%	57%	65%
Meet with community leaders	46%	45%	34%	39%
Other	24%	33%	17%	22%

It is interesting to note the similarity between the Tuskegee and Los Angeles responses with respect to using SIDS resource kit materials for presentations, handing out kit materials, and meeting with community leaders. Tuskegee summit participants were more likely than participants at the other two summits to plan to talk with friends and neighbors. Although this finding might reflect upon the summit itself, it also might reflect other factors such as community culture. Respondents in Detroit, compared to those at both other sites, were generally less likely to report plans for any one particular activity.

Audiences to be targeted by these activities included:

- Hospitals and clinics
- Health care professionals (e.g., nurses, neonatal medical workers)
- Academic institutions (e.g. high schools, junior colleges, state education systems)
- Local government (e.g. city health councils, economic opportunity boards)
- Government officials (e.g., state senator from Nevada, chief of police)
- Faith communities (e.g., ministers)
- Voluntary health organizations (e.g., March of Dimes)
- Local media
- Parents (e.g., welfare and low-income mothers, unwed pregnant women)
- Child care providers
- Local chapters of partner organizations

The SIDS summits prompted participants to consider more specifically what they could do when they returned home. Many individuals appeared to have clear ideas about what they could do after the

summits. For example, the Honorable Lucenia Williams-Dunn, Mayor of Tuskegee, spoke at the Tuskegee summit and vowed to share SIDS information with other mayors and to challenge them to do something in their own cities and towns. During breakout sessions and onsite interviews, participants mentioned the following actions that they planned to take after the summit:

- Participants at the Los Angeles summit concurred with a recommendation to advocate for a uniform policy regarding death scene investigations.
- A participant from Reno, Nevada, planned to advocate for her county to track SIDS in African Americans. She also intended to meet with her pastor and arrange a meeting with church women in their twenties to give them information about SIDS.
- A biology teacher from Oakland, California, said that she would incorporate SIDS information into her curriculum.
- An AKA member from Nevada commented that she would be joining a group that will meet with legislators to promote a statewide initiative on minority health, and she would incorporate SIDS as part of the initiative.
- A retired pastor from California planned to give materials to women in his church and community to disseminate.
- The president of the Black Student Union at a college in California said he would hold a campus program to disseminate information and would forward the information to childcare centers.
- A participant from Chicago State University intended to host a SIDS seminar on the campus.
- A participant at the Detroit summit planned to distribute information to vulnerable populations.
- A participant who worked for a nonprofit service organization in Flint, Michigan, that deals with infant mortality was going to order more resource kits to help inform its more than 1,000 registered clients.

Feedback on format and content

Because the ability to involve audiences affects the level of impact of an information dissemination effort (Flora et al., 1997), the following participant comments indicate that with respect to being motivational and empowering, the summits were successful.

Sessions were motivational and empowering

- Very stimulating and empowering. (Tuskegee)
- I am excited and motivated by all the sessions. I found them all to be important. (Los Angeles)
- This summit was stimulating and informative. I found it to be very conducive to gaining information and networking. (Los Angeles)
- Loved the passion spokespeople demonstrated during their talks. I feel this was a very informative session. (Los Angeles)
- I enjoyed this workshop and I am excited to go back into my community and help others to be more informed. I cannot begin to tell you how great this workshop was. (Tuskegee)
- It was a wonderful experience being in the presence of so many powerful African American women, from so many different areas, coming together with one main purpose and goal. (Tuskegee)
- This was an awesome experience. All the power women made me proud to be black and female and passionate about the journey to save our babies. (Tuskegee)
- Excellent to help us realize the problem and start to correct it where we can. (Detroit)

- I will continue to share this information with my community to keep babies safe. (Detroit)
- This summit was powerful, motivational, and empowering. Hats off to NICHD, NCBW, and AKA. I am thankful for the opportunity. (Tuskegee)
- I have been truly enlightened. (Los Angeles)
- I can only say that there should be more meetings like this taking place. (Los Angeles)
- I really enjoyed this meeting, looking forward to the next one. (Tuskegee)
- Overall, this was a fantastic summit with excellent speakers and a grand display of empowered black women. Very informative! (Tuskegee)
- Empowered and informed—a new way to give children life and a future. (Los Angeles)
- This summit has inspired me to not give up. . . Today has inspired me to use my skills to help make a difference in my community by teaching and training young mothers. Learning equals change. (Los Angeles)
- I am inspired by the communal commitment shown at the SIDS summit. (Los Angeles)
- I am most grateful to the women who saw a need for us to reach out to our communities with SIDS. Thank you again. I will take this back to my community in Kitsap County and to the State of Washington. (Los Angeles)
- I feel honored to be given the opportunity to join this conference, and I leave with lifesaving knowledge that I will put into action! (Los Angeles)

Data from open-ended questions on the reaction forms indicate that many participants found the SIDS summit to be well organized and an important, meaningful, and motivational experience. The following are quotations taken from the reaction forms:

Summits were well planned and organized

- I like the format and content of the summit, 1 and 1/2 days is ample time to provide viable information, educate network in a not so very formal setting offered ease of exchange. It can only grow to higher heights. (Tuskegee)
- This was one of the most well planned event sessions I have attended. (Los Angeles)
- Well-organized and informational sessions. Really appreciated all the hard work that went into the planning of this conference. Sessions were motivational and practical. (Tuskegee)
- This has been one of the most organized and conference attendee attentive I have attended. (Los Angeles)
- The structure and planning of the seminar was exemplary. (Los Angeles)

Materials and presentations were clear

- I liked that the material is clear enough and understandable so that we can train others. (Los Angeles)
- Thought materials were so well laid out and made it so easy to train others. (Detroit)
- Excellent presentation skills really made audience/attendees want to participate, keep up the great work. (Los Angeles)
- This was great . . . quality presenters. (Los Angeles)
- Overall, this was a fantastic summit with excellent speakers and a grand display of empowered black women. Very informative! (Tuskegee)

Impact on number of requests for resource kits

The *Resource Kit for Reducing the Risk of Sudden Infant Death Syndrome (SIDS) in African American Communities* was well received, and many attendees took away more than one kit, with the promise to order more upon their return to their communities.

By January 2003, 4,754 requests for the SIDS resource kit had been received since distribution began in April 2001. Between March 2003 and November 2003, 1,977 orders for the kit were received, with an average monthly order of 220 kits. The peak month for kit requests in 2003 was June (410 requests), followed by April (352) and August (323). Exhibit 7 presents the SIDS Resource Kit monthly distribution for all available data between March and November 2003.

EXHIBIT 7
MONTHLY DISTRIBUTION OF SIDS RESOURCE KIT

Date	Kit	Brochure	Magnet	Video
March 2003	142	35,445	101,439	1,719
April 2003	352	65,719	93,046	1,128
May 2003	94	19,898	127,218	1,431
June 2003	410	27,849	164,484	1,936
July 2003	76	76,924	248,397	5,016
August 2003	323	200,081	202,395	1,582
September 2003	143	222,609	142,495	753
October 2003	273	68,719	82,171	242
November 2003	164	20,580	97,126	206

Note: February 2003 data are not available.

Participants' suggestions for improving the summits

In response to open-ended questions on reaction forms and through follow-up interviews, participants provided suggestions for improving the summits. These suggestions, summarized below, addressed the length and format of the events, the information provided, speakers and participants, and meeting logistics.

Format

- The most common suggestion for improvement was to make the summits longer, with suggestions to extend the 2-day meeting to a weeklong event.
- Some participants suggested including parents who have been affected by SIDS among the speakers.
- The most common suggestion for improving the breakout sessions was to allow more time for the workshops and to provide the opportunity for participants to attend at least two different sessions.
- Breakout sessions also could be improved by incorporating more hands-on activities, such as more open discussion time, more role-playing, more opportunities to share "best practices," and practical demonstrations of the technique for putting babies safely to sleep.
- Several participants suggested designating more networking opportunities during the meeting.

Participant recruitment

- Comments on reaction forms indicated that participants at all three summits thought the events should be more inclusive, with larger numbers of attendees—provided that facilities were planned to accommodate them. Whereas some respondents suggested that the meetings should be open to the public, most suggested specific types of people who should be included as participants. Suggestions for additional invitees included young mothers and fathers, pregnant mothers, teens, nurses, school and vocational counselors, clinic technicians, Lamaze childbirth teachers, and representatives of outreach organizations.
- Several participants suggested removing the "color" issue and acknowledging that SIDS disproportionately affects other races and ethnicities.
- Several participants emphasized the need to provide more advance notice about the summits and to use publicity more effectively to advertise the event to more potential participants.

Presentations and materials: content

- Information provided at the plenary and welcome sessions needs to include more specific directives for action planning. Particular examples of program accomplishments, "best practices," and organizational-based strategies would be helpful.
- The information provided at the summit could be improved with the addition of handouts that summarize statistics and other content from the presentations.
- Another concern was the need for more information on SIDS bereavement issues. As one participant noted, "There is a need to be prepared to deal with someone who has lost a baby to SIDS; you cannot just give these people information and walk away. Bereavement is not specifically dealt with in the resource kit, although there are resources for bereavement in the back of the training guide." Several participants suggested including testimonials from parents affected by SIDS.
- Although one comment noted that limiting the discussion to SIDS helped focus and concentrate efforts, many participants expressed an interest in having the summits address other topics. Suggested additions included issues related to maternal and child health (e.g., infant mortality, teenage pregnancy, breastfeeding, the role of men in childrearing) and health disparities in the African American community (e.g., HIV/AIDS and other sexually transmitted diseases, diabetes, cardiovascular disease, obesity, drug abuse).

Workshops appeared to be generally helpful with basic information, but participants wanted more specific hands-on experiences of how to use the resource kit and how to better reach their communities. Overall, more information was needed on exemplary practices and concrete action items for next steps.

Follow-up activities

- Continue to gather, update, and disseminate information, including current research findings.
- Provide feedback on progress, such as annual meetings to present and discuss outcomes and celebrate accomplishments.
- Conduct additional summits in different cities over a period of time.
- Consider reconvening the summits to celebrate and assess the partnership's accomplishments, take stock of what has occurred, and consider how to best follow up with next steps that can serve as catalysts.
- Take the workshops to community-based organizations and parents.
- Use the summit format to address other health issues in the African American community.
- Work with "natural" partners (secondary partnerships), such as mayors' offices and health departments in different cities and states.

- Enlist mattress manufacturers in observing minimum specifications for their products and becoming partners in promoting the effects of mattress size.

Partners' suggestions for improving the summit process

Input from the interviews with the partners provided additional insights about ways to improve the summit process. These stakeholder recommendations addressed issues such as maintaining and expanding the momentum of the summits and continuing to empower participants. Partner suggestions included the following:

- The summits should have a better gender representation (men) and greater diversity of people, even within the African American community (e.g., youth).
- Although all participants received the SIDS resource kit, some participants wanted a takeaway plan to foster self-motivation over the long haul and remind them of their experience at the summits.
- The partnership needs to have a tri-leadership process agreement in place to ensure corporate memory.
- Planning monies might provide seed money for the partner organizations.
- A formal mechanism needs to be in place to capture SIDS risk reduction activities. The summits reached a group of people and told them they can have an impact on their future. Providing them with the knowledge of how this work is progressing would be empowering.
- To be successful, the partnership needs to have incremental gains and celebrate these successes as they occur, step by step.
- The partnership needs to learn more about dissemination—how people can get more information, kits, and other resources once they get back home. It is important to build a sense of empowerment for local groups to do this on their own without being dependent on Stacy Scott and In Black Print.
- The partnership needs to link with other key organizations that have resources and a track record in local African American communities.

Feedback and Refined Strategy

After each SIDS summit, the external evaluators compiled their preliminary findings from participant reaction forms and interviews and shared findings at a debriefing session with the partner organizations. Evaluators also prepared and provided each partner organization with a case study report that summarized the observations, interviews, and follow-up calls. This ongoing input after every completed summit allowed partners and other planners to continually refine the summit process and build on the successes of preceding events. Key areas in which this feedback helped to refine strategy are described below.

Introductory presentations

Comments from participants indicated that some were overwhelmed with information and statistics about SIDS during the opening session. After the Tuskegee summit, Dr. Maddox adjusted her presentation to make it more succinct and focused on key points. She also used charts effectively to help demystify the data she presented.

Plenary sessions

Participants' comments and evaluators' observations led planners to conclude that participants needed more explicit information to help them translate summit information into community action. One evaluator suggested that plenary panelists provide specific examples of community program accomplishments and information dissemination strategies as a follow-up to Dr. Maddox's presentation. Although similar comments from Los Angeles and Detroit participants indicate that subsequent panelists did not adequately address this need for practical insights, summit agendas began to allot more time for questions and answers following plenary sessions. This interaction allowed speakers to present more specific and relevant information.

Breakout sessions

External evaluators observed that the breakout sessions in Tuskegee were one-dimensional and followed a traditional lecture style. It also was noted that facilitators failed to provide creative and flexible instruction on the utility of the kits within the context of the session topic. For example, the activist/policy session included no concrete discussion of how participants could substantively change the policy environment of their local community to encourage a *Back to Sleep* approach and no solicitation of suggestions on how to start letter-writing campaigns to local officials on SIDS issues. Evaluators suggested that the breakout sessions be less didactic and more interactive, with a give-and-take format.

As a result, facilitators in Los Angeles and Detroit made several adjustments to their breakout sessions. All trainers began to provide handouts of their presentations, and most used PowerPoint presentations. Facilitators encouraged participants to ask questions and solicited their feedback and input on a variety of issues relevant to the session's area of focus. For example, in the advocacy/policy sessions, participants were now asked what they would recommend as an effective action to advocate for changes in SIDS policies in their respective communities. Participants' stories and experiences often were shared, providing "teachable moments" for everyone at the session. Facilitators also started to use more creative and concrete ways to effectively explain technical terms. For example, to demonstrate that the slats in cribs should be no more than 2½ inches apart, the trainer compared that measurement to the diameter of a can of soda. Facilitators also incorporated more interactive activities, such as role-playing, into the trainings.

Closing session and celebration of life ceremonies

Comments on reaction forms indicated that the religious service conducted during Tuskegee's "Celebration of Life" ceremony might have inadvertently offended some participants because of its religious fervor and evangelical approach. Some participants expressed that greater sensitivity should have been given to the fact that people come from different Christian faiths and others may not be Christian or religious. Moreover, the length of the ceremonies precluded conducting a closing session, which had been scheduled. Consequently, there was no opportunity to provide participants with last-minute discussions, comments, or reviews of the day's events.

Concerns about the closing ceremony were taken into consideration in planning the Los Angeles summit and resulted in an ecumenical service led by clergy and leaders from different faiths. Feedback from participants indicated that the session felt spiritual without excluding anyone because of their religious orientation. Among the feedback from participants was a comment that this type of closing activity was important when an emotionally laden topic such as SIDS is involved. The Los Angeles ceremony also invited participants to verbalize their commitment to SIDS reduction efforts as a group and give their individual testimonies, which helped personalize the summit's impact. The Detroit summit returned to the Tuskegee approach, with a motivational sermon. The closing session did include a final discussion by Dr. Maddox and other principal leaders about the overall mission of the summit.

Logistics

The contractor, IQ Solutions, and the partners all learned to adjust their procedures to adapt to difficulties in accurately predicting the number of participants who would actually attend the summits. The adjustments after Tuskegee allowed meeting coordinators to accommodate participants who came from an average of 13 to 15 states and filled, often at the last minute, 7 to 12 buses at each summit. By the time the Detroit summit was held, most logistical problems had been resolved and arrangements went smoothly.

However, unlike the Los Angeles summit, with its hotel located within a mall, and the Tuskegee summit, with nearby historical attractions, the somewhat remote site of the Detroit summit (held in Dearborn rather than the immediate Detroit metropolitan area) was the source of negative comments.

Breaks and networking opportunities for participants

Following suggestions from participants of the Tuskegee summit and evaluators, the Los Angeles and Detroit summits incorporated break periods into the agenda and allowed more time during the receptions and luncheons for networking with other participants. However, comments from participants at all three summits indicate that even more networking opportunities would have been welcome.

Summit Short-Term Outcomes

To meet the goal of encouraging a significant regional population to engage in SIDS risk reduction activities, each summit needed to become a catalyst for subsequent efforts. The partnership envisioned that each summit would generate a multitude of local activities as well as other summits held at the state or local level. The final component of the process evaluation model represents initial attempts to determine the impact of the SIDS summits by examining short-term outcomes in terms of follow-up activities documented by September 2003. Information on short-term outcomes was collected in two-month follow-up interviews conducted with nine participants (three from each summit). These interviews suggest that the summit was successful in preparing and empowering participants to conduct SIDS education activities in their communities. The following summarizes some of their reflections on the summit, activities that were already planned or conducted within the two-month follow-up period, and partnerships that were in place for future activities.

Reflections on the Summit

Valuable information. Respondents felt that the information provided at the summit was adequate and helpful and equipped them with information and materials to provide to their communities. Six individuals specifically mentioned that they were better informed about SIDS, even though some of these people already were knowledgeable about the topic. Three participants mentioned being better prepared to train others, including one person who felt better equipped to reach out to different populations, including young parents with infants. One individual at the Detroit summit stated that she needed more statistics about SIDS before she felt fully prepared to conduct workshops on her own.

Collaborative efforts. Respondents appreciated the collaborative aspects of the summit and hoped to create new collaborations in their communities. Many respondents were already using previous organizational connections to collaborate on information dissemination. Although some respondents appeared to be the major force behind activities, others had already established networks to work with in their communities.

General impressions. Each respondent participated in the entire summit and felt that the summit met and, for the most part, exceeded their expectations. The summits were described as compelling events and well-organized, wonderful conferences.

Planned or Conducted Activities

Information gathered during the follow-up interviews indicates that nearly all of the interviewees were actively involved in a SIDS-related event. Highlights of these activities include the following:

- Conducting SIDS risk reduction workshops for a variety of audiences, including mothers of infants at a low-income apartment building
- Working with local and regional hospitals on SIDS education
- Incorporating SIDS information into curricula of local colleges and local chapter programs for mothers
- Making presentations on SIDS to local councils, hospitals (for neonatal medical workers), leadership conferences, and at-risk parents
- Distributing SIDS resource kits or information to local chapters, schools, clinics, local public officials, voluntary health organizations, ministers, and coworkers and professional colleagues, and at health fairs and a minority health conference

Exhibit 8 provides more details on the specifics of these activities.

One of the more immediate summit follow-up activities was a series of SIDS Sunday events sponsored in Detroit by the AKA in June 2003. The effort was launched on June 1, 2003, the day after the Detroit SIDS summit, when summit participants joined the congregation of the Hartford Memorial Baptist Church to hear Dr. Maddox and Rev. Dr. Adams speak about reducing the risk of SIDS in African American communities.

The launch of SIDS Sunday set the stage for specific follow-up activities and implemented an accountability process whereby actual statistics about these activities could be gathered and outcomes could be measured. In addition to this kickoff SIDS Sunday service, the AKA sent more than 200 letters and packets of information to churches in the Detroit metropolitan area asking pastors to share information regarding SIDS during June from their pulpits, in their church bulletins, and with nurses and caregivers in daycare centers and nurseries. After the summit, the Detroit SIDS Committee conducted follow-up calls with the 200 churches in the Detroit metropolitan area and found that 65 of the churches held a SIDS Sunday and that information had been shared with more than 14,000 individuals through these faith institutions. Another 95 churches stated that they were going to have a SIDS Sunday later in the month. The Detroit SIDS Committee also planned to distribute information regarding SIDS at the National Baptist Congress of Christian Education in Detroit on June 17-20, 2003. The AKA estimated that SIDS Sunday events in June reached about 40,000 people in the Detroit area.

Additional SIDS Summits

As a direct result of the SIDS summits, several cities and states are considering hosting a SIDS summit or similar event. In the three months following the Detroit summit, such events already have occurred in Cleveland and Columbus, Ohio; Indianapolis, Indiana; Jacksonville, Florida; and parts of Mississippi. Several summits are currently under development. In addition, the Chicago AKA chapter received a grant to host a SIDS conference in the Chicago area with other organizations.

EXHIBIT 8

Tuskegee	Los Angeles	Detroit
The State Ambassador for Tennessee has: • Worked with local and regional hospitals (e.g., Children's Hospital, Hutchinson Medical Center) on SIDS education • Made a presentation on SIDS to the citywide health council • Been asked to give a presentation on SIDS to Children's Hospital for at-risk parents and neonatal medical workers. In addition: • Her local NCBW has approved her moving forward with SIDS as an action item as part of NCBW's public health initiatives. • She will be dealing with the local media to put on public service announcements.	A participant from Wyoming has: • Shared SIDS resource kits with chiefs of police, the March of Dimes, and a homeless clinic • Distributed information in four high schools • Talked to at least 100 individuals about SIDS since returning from the summit. Plans include sharing kits at a minority health conference.	• A participant recently had a leadership conference of the NCBW in Las Vegas, where all 200 participants attended a half-day of SIDS orientation and presentations. • Her NCBW chapter conducted a workshop on SIDS for mothers and infants at a low-income apartment building. • Her chapter is adding a SIDS component to an existing curriculum for a baby shower activity that works with unwed, pregnant, indigenous mothers.
The State Ambassador* for Florida is: • Incorporating SIDS information into the curriculum at Pensacola Junior College, particularly for nursing students and students in the child development academic program • Working on a county health fair that will host a SIDS information booth and workshops on the correct sleeping position for infants (other bus participants are helping her) • Trying to put SIDS information in the state education curriculum so that the information reaches students beyond the Pensacola area.	A bus captain from Las Vegas has: • Led a couple of workshops using the SIDS resource kit • Shared information with a Nevada state senator who has experienced a personal loss to SIDS and is interested in being involved in local efforts. She also reported that: • The Black Nurses Association is sharing SIDS information with its members and patients • The Economic Opportunity Board that runs Head Start in Las Vegas is working with parents and families • Local chapters of organizations whose members attended the summit have found ways to collaborate on the project as well as work through the program foci of their individual organizations. She plans to call together summit participants to develop a strategy and meet with the state senator who wants to help advance their efforts.	A hospital administrator from the Midwest plans to: • Work on an upcoming SIDS conference in Ohio, cosponsored by the AKA • Continue to spread accurate information about SIDS to coworkers and others in her profession.
A bus captain† has: • Given two workshops on SIDS • Distributed about 20 SIDS resource kits. She also will be: • Working with local agencies on SIDS education, including her local affiliated agency, a partner organization that works with welfare mothers • Meeting with other persons from her community to put together a strategy for getting out information to churches and the local neighborhood.	The State Conference President for Idaho, Nevada, and Utah has given SIDS resource kits to eight branches of the NAACP.	A participant from the Ohio area: • Worked on a lunch event in Columbus, indirectly related to the SIDS state summit in Cleveland • Gave the SIDS Sunday packet to her minister.

∗ State ambassadors were individuals who coordinated participants from their jurisdiction for the sponsoring host organization.

† Bus captains coordinated transportation for participants to a SIDS summit.

Partnerships

New partnerships reported in follow-up interviews included those forged at the summits among participants who shared travel and/or other experiences at the events. As shown in exhibit 8, for example, one state ambassador noted that Tennessee participants at the Tuskegee summit were constantly in touch with each other. She had asked the 38 to 42 people on her bus to serve as caseworkers for SIDS within their respective professional environments, which included hospitals, schools, and local government.

Another Tuskegee attendee reported that Florida participants who shared her bus are helping her with a health fair at which she plans to disseminate SIDS information. These women have formed an ad hoc committee to continue the momentum of getting the word out on SIDS. A Detroit summit participant has remained in touch with others who are part of the same NCBW chapter and attended the summit together. This participant also was in contact with AKA sorority sisters in other parts of the country about SIDS issues. Thus, it would appear that the practice of traveling to the summits in groups fostered future partnerships by introducing participants to other individuals with whom they could now collaborate in their communities.

Other new partnerships generated at the summits included collaborations between local and national organizations. A Tuskegee summit participant intends to work on SIDS education with local agencies, including the agency with which she is affiliated—a community-based partner organization that works with mothers on welfare. A participant at the Los Angeles summit noted that organizations whose members attended the summit (local chapters of The Links, Delta Sigma Theta Sorority, the NCBW, and the AKA) have found ways to collaborate on the SIDS project as well as to work through the program foci of their individual organizations. She also reported that the Black Nurses Association is now sharing SIDS information with its members and patients.

Follow-up interviews indicate that the partner organizations continue to play a role in SIDS risk reduction efforts in some areas. A Tuskegee participant reported that her local NCBW chapter has approved her moving forward with SIDS as an action item as part of the NCBW's public health initiatives. A local NCBW chapter in the Detroit area is following up with SIDS workshops for mothers with infants in a low-income apartment building and will add a SIDS component to an existing curriculum designed for work with unwed, pregnant, indigenous mothers through a baby shower activity. A State Conference President of the NAACP who participated in the Los Angeles summit stated that the organization's Health Committee, Veterans Affairs, and AIDS program areas will be used to disseminate SIDS information to NAACP members.

Reflections on the Model

The Partnership for Reducing the Risk of SIDS in African American Communities has made progress toward accomplishing all its goals for the SIDS summits. The short-term outcomes include SIDS risk reduction activities that have engaged regional involvement of the African American community, as well as new partnerships and alliances based on relationships developed during the summit process. Summit participants uniformly described an increase in their knowledge of SIDS and their ability to work for policy or behavior change in their communities. The partnership itself provides a model of collaborative efforts to secure resources. The following observations from stakeholders and external evaluators offer additional insights about the success and potential of this model for efforts to reduce risks for SIDS, and possibly other health disparities, within the African American community.

Stakeholders

Interviews with key stakeholders—representatives of the partner organizations and the NICHD—emphasize many of the strengths of the partnership and the SIDS summit process. Key elements identified by these individuals include the following:

- *Collaboration among the partners.* Bringing the three partner organizations together was, according to one partner, "the most powerful component" of the process. This collaboration set the standard for the leadership and cooperation that is needed before a variety of other participants from the community will come together. By not insisting on their individual prominence, the partners demonstrated that the cause of SIDS risk reduction was "bigger than any one of our organizations. . . . Our organizations are mere conduits to have others participate." Together, the partners formed a "brain trust that was respected and harnessed energy, collectively."
- *Inclusiveness of the process.* By being inclusive in its tactics and its invitation for others to participate in the summits, the partnership was able to reach beyond the constituencies of the individual organizations and build broad support in communities. As one partner explained, "If, after major outreach, all the people who come look and think like us and are exclusive to our various chapters, then we are not doing something right. . . That's the purpose of working across organizations rather than merely within organizations. . . To do it otherwise means that the coalition was not necessary."
- *Diversity among the partners.* Although collaboration and inclusiveness are necessary, the unique qualities of each of the partners were also an important strength. The African American community is not monolithic, and the three organizations offered different paths to reach diverse groups and sectors. One partner noted, "The beauty of a coalition is that we impact and intersect in different ways and at different points. That's what makes the coalition more powerful than any one of the organizations it represents. No group can do it or should do it on its own."
- *Continuity.* According to each of the partners, continuity was key to making the summits successful. Although history of the African American outreach initiative goes back to 1999, only the three partner organizations remained actively involved in the process that led to the SIDS summits. Dr. Maddox's ongoing participation in the process offered another element of continuity. Partners viewed her involvement as crucial: "If not for her, the summits never would have been accomplished. She made us stick together and form a continuing team."
- *Flexibility.* The NICHD's willingness to explore nontraditional approaches to a partnership between the federal government and community-based efforts was an important factor in securing buy-in from the three partner organizations. Partners praised the Institute for facilitating leadership from within and letting the organizations "shine and do their best." One partner noted that the partnership was "an educational process for the federal government about how to work with community-based organizations without dictating the process." The organizations appreciated this ability to offer support and an equal voice in the partnership. One partner stated, "People are willing to work if you involve them, facilitate their involvement, and do it with compassion, sincerity, and respect for their ability to come through. This is exactly the ingredients that the NICHD provided to the partnership."

At the end of the three summits, the partners expressed enthusiasm for continuing the effort:

- We have created a model that we must use. . . It is a new way to maximize limited resources and reach more people.
- It was uplifting and educational to people, and it was capacity building with grassroots organizations. . . This effort will not be lost, and we will see the benefits of it over time and through a long process.

The leaders of all three partner organizations appreciated the need to continue the message of the SIDS summits in some form of follow-up activity. They also felt that the summit process, as presented in

exhibit 1, could be easily adapted to other health issues within the African American community. The partner leaders considered the ability to replicate the structure of the SIDS summits for other pressing health concerns to be one of the greatest contributions of the summits, representing an important and continuing investment in the future of the African American community.

External Evaluators

External evaluators became involved in the SIDS summit process during the later stages of planning for the events, after major decisions about the summit agenda and invitees already had been made at the Partners Forum. Without direct observation of the earlier partnership development stages, evaluators were limited in their ability to fully evaluate the specific role of the partnership in the process that led to the SIDS summits. However, an assessment of the summits and a review of the short-term outcomes reported to date indicate that the collaboration between government and the private sector that constituted the Partnership for Reducing the Risk of SIDS in African American Communities was successful in using federal guidance, materials, and financial support to help community-based organizations disseminate far-reaching messages to the target communities. In addition, the use of consultants with expertise in community-based SIDS outreach, conference management, and evaluation was an important factor in securing partner buy-in, facilitating communication and fiscal management, and conducting well-organized events that were continually improved. The following summarizes some of the valuable aspects contributing to or resulting from the summits.

- *Well-matched organizations as collaborators.* Evaluators noted that it was relatively easy for the three partner organizations and their local chapters to become involved and enthused about an issue that previously was not already a part of their respective agendas. Factors contributing to this readiness may have included the match between the general concerns of women's organizations and the issue of infant mortality, the compelling nature of SIDS itself as an issue, and the disparity in SIDS rates in African American communities. It might be interesting to explore whether an issue needs to be culturally specific to evoke such a willingness to participate actively.
- *Cultural sensitivity.* Following each of the three summits, a summit site report was written presenting the observations and data collected from participants and stakeholders. These reports indicate that culturally appropriate elements—such as presentation topics, activities, entertainment, and food—contributed to the success of the events. Several comments from participants highlighted a cultural aspect of the empowerment experienced at the summits. For example, a Tuskegee participant noted on her reaction form, "All the powerful women made me proud to be black and female and passionate about the journey to save our babies." A participant at the Los Angeles summit testified in the closing ceremony, "This summit was further confirmation of the beauty and resilience of our people, African Americans." It may be that reaching people at a place where they were most comfortable helped engage them in the process.
- *Value of the formative process.* Evaluators also noted that the SIDS summits were not a series of independent events, but rather a process that transcended each meeting, picking up momentum from one event to the next. Moreover, the participants did not view the summits as single events but as a process that was almost independent of the organizations to which they belonged. One aspect of the gathering momentum was the development and strengthening of leadership through participation in the summits. For example, evaluators observed that a workshop participant at one summit would later assist in the formation of another workshop at a subsequent activity or summit event.
- *Developing organizational infrastructure.* As the partner organizations themselves noted, their capability for disseminating health messages has been strengthened and has the potential

to help them address other health disparities in the African American community. For example, the SIDS partners may want to consider how they can use the infrastructure developed for the SIDS summits to disseminate messages about the risk factors associated with childhood obesity and diabetes or other health issues that affect African American children. The summit process also can serve as a model to reach other population groups.

A review of the findings from participants and stakeholders strongly suggests that the summits were successful. From the evaluation team's observations of the process, the model provided a solid structure that facilitated both development of the partnership and implementation of the summits, along with evaluation of the process. Typically a logic model such as this provides the framework for the development of a program or specific activity such as these summits. It works best when it is a formative tool for planning and evaluation that allows for changes to be made to the model as feedback is provided. This was seen during the summit process as each meeting benefited from the lessons learned from those before it.

Having completed the process evaluation, it is also possible to review the model to identify elements that might be changed. The evaluation team noted that two areas of the model could not be fully documented. This lack of documentation may reflect a more informal approach on the part of partners or the fact that the evaluation began after the partnership was already formed. However, it appears that the development of the partnership and an underlying organizational structure did not occur through the application of a rigorous planning process, but rather through an informal concurrence among the key players. This type of development is difficult to document, but does not diminish the importance of these elements. Thus, it is not suggested that the model be revised, but that future initiatives perhaps identify factors that enhance the positive development of the partnership and organizational structure. This approach would require intentional documentation of these two processes. The success of the replication of this model will also depend on the types of organizations applying it to their task. To best understand how useful the model is in other situations, its implementation should include an evaluation that carefully documents social and organizational input as well as variations that may occur in the processes followed.

Implications for the Outcome Evaluation

The purpose of the process evaluation was to document and better understand the partnership development, planning process, and activities that took place at each SIDS summit by capturing the viewpoints of a variety of meeting participants (attendees and partnership members) about what was accomplished at each meeting. In general, the evaluation shows that the summit process was successful in many areas. The gradual, yet intentional development of the partnership among the community-based organizations as well as between these organizations and the NICHD provided a strong and broad base from which to launch the summits. Participants from across the nation took part in the summits. The planning and implementation of the logistics for the three summits resulted in meetings that were culturally sensitive, motivational, educational, and enjoyable. Participants left with intentions of carrying the SIDS message actively back to their communities.

Although this information provides an in-depth understanding of the summit process and perceptions of participants and planners regarding its success, an evaluation of related outcomes is the best way to measure the success of the summits in reaching their goals. Two months following the summits, nine participants were interviewed to gather information on some of the follow-up activities that occurred when these individuals returned to their communities. This documentation provides a hint of what might be expected from a broader and more complete evaluation of outcomes.

There are two broad outcomes to be explored. The first focuses on the value of the partnership between community organizations and the federal government. Similar partnerships have been initiated for other public health communication efforts. However, many of these partnerships have not been formally evaluated with respect to their contribution to the success of a campaign or the elements of their development that make them successful partnerships. The SIDS summit process evaluation began to collect information on the partnership process involved in planning and implementing each of the three events. This work can be expanded to gather more detailed retrospective data and to document elements of the continued success of the SIDS summits in African American communities. The second outcome on which evaluation efforts can focus is the impact of the summits on the knowledge, attitudes, and behaviors of participants. This work would include understanding and documenting whether the meetings resulted in an increase in SIDS prevention activities at the regional, state, and local levels.

The following section describes anticipated outcomes and briefly discusses the methodology for data collection.

FROM PROCESS EVALUATION TO OUTCOME EVALUATION

To understand the movement from process evaluation to outcome evaluation, the logic model used to describe the process evaluation can be taken one step further. Currently, the model incorporates summit short-term outcomes that focus on workshops for target audiences; general changes in knowledge and attitudes among summit participants; and participation and sponsorship of additional events and activities. These outcomes are relatively limited given the two-month period during which they might have been achieved. Exhibit 9 presents questions and indicators focused on understanding the success of the partnership or collaboration model and the success of the summits in changing knowledge, attitudes and behaviors of community leaders. These questions and indicators could be utilized in a more comprehensive evaluation of longer-term outcomes.

A logic model that extends the existing process evaluation model (exhibit 1) to include longer-term outcomes would include the above elements in a final, fifth column, as presented in Appendix G. An evaluation of the indicators would provide feedback to both the partnership development and operational strategy components of the model.

Question	Indicator	Data Source
Retrospective Reflections on Value of Partnership for the Summit		
What was the perceived value of the partnership for stakeholders?	▪ Perceived value for summit ▪ Perceived benefits (e.g., collaborative thinking; collaborative logistics planning; brought in more participants; collaboration among local participants from different organizations; serves as model for ongoing interorganizational collaboration; wider dissemination of message; established relationships with other organizations involved with women and children; greater recognition and buy-in to SIDS risk reduction at local level) ▪ Perceived costs (e.g., lack of organizational control and organization-specific agenda; investment of fiscal and staff resources) ▪ **Utility of model for future initiatives**	▪ Partner Organizations ▪ NICHD
What was the perceived value of the partnership for participants?	▪ Perceptions on value of partnership: — Knowledge of existence of partnership — Value for successful summit — Perceived benefits (e.g., brought together different types of participants; provided opportunity for broader or different approaches; demonstrated value of partnering with other similar organizations; demonstrated value of partnering with government organizations; empowerment to effect change and eliminate disparities) — Perceived costs (e.g., lack of coherent group; difficulty in applying lessons to organizational missions)	▪ Participants
Continuation of Collaborative Relationships		
Did the model influence continued partnership with respect to SIDS?	▪ Post-summit SIDS-related collaborative activities with partners — Type and level of contacts — Number and type of activities, target audiences	▪ Partner Organizations ▪ Participants
Did the model influence other initiatives within this group of organizations?	▪ Post-summit non-SIDS-related collaborative activities with partners — Type and level of contacts — Number and type of activities, target audiences	▪ Partner Organizations ▪ Participants
Did the model influence additional collaborations? (These would be new collaborations that were influenced by the success of the summit collaboration, not collaborations already in the works.)	▪ Post-summit collaborative activities with other organizations — **Type and level of contacts** — **Number and type of activities, target audiences** ▪ Influence of the collaborative summit experience on these collaborations: — New or continued topic — Similar organizational styles or missions — Existence of a shared vision (formal/informal) — Formal/informal partnership — Established collaborative organizational structure — Established operational strategy — Established communication procedures	▪ Partner Organizations ▪ Participants

Question	Indicator	Data Source
Changes in Knowledge, Attitudes, and Behaviors of Community Leaders		
Did the summit result in a change in knowledge attitudes and behavior reflected in new SIDS-related activities?	▪ List of new activities categorized by type of activity (media campaign, education campaign through existing venue, education campaign through new venue) ▪ Number of resource kits ordered by partner organizations, participants, summit regions ▪ Usefulness of resource kits and how they were used	▪ Partner Organizations ▪ Participants ▪ NICHD
Did the summit empower participants to become initiators and collaborators of new SIDS activities?	▪ Initiator of activity (person or organization involved in the summit or other) ▪ Collaborating organizations/individuals, nature of collaboration	▪ Partner Organizations ▪ Participants ▪ NICHD
Did the summit result in the dissemination to new target audiences or to those at greatest risk?	▪ Target audiences: Organizational level or population? — If organization, describe type, size, membership — If population, describe size of audience and demographics (e.g., gender, ethnicity, income level, education) ▪ Selection methods—general membership or through risk or needs assessment (community profile) ▪ Location of activity (type of facility and address)	▪ Partner Organizations ▪ Participants ▪ NICHD
Is the summit continuing to inspire the planning of new SIDS-related activities?	▪ List of activities	▪ Partner Organizations ▪ Participants ▪ NICHD
Are there any data demonstrating community-level changes?	▪ Available local evaluation data on community sleep-position practices ▪ SIDS-related mortality data (trend data to be collected in the future)	▪ Local evaluations of activities ▪ National/state mortality statistics

NEXT STEPS

The goals of the evaluative process will be achieved through two major types of activities. One will involve a survey of meeting participants; the other will rely on more in-depth, one-on-one interviews with key stakeholders. The methods to be considered for an outcome evaluation need to reflect the lessons learned from the process evaluation. To gather information from stakeholders, interviews need to be brief and concrete. All stakeholders are extremely busy and unlikely to respond to a survey. The interviews should be guided using a protocol that will assist the interviewer in keeping the conversation on track and ensuring that all topics are covered.

Data collected from participants will best be collected through a more formalized survey process. Although a written survey could be used, a telephone survey conducted with a representative sample of the participant population is suggested. The rationale for the telephone interviews is that community-based populations do not easily respond to written questionnaires, especially mail surveys. Furthermore, the interview process will allow for greater in-depth inquiries through open-ended questions, such as questions to obtain detailed information about post-summit activities. These data are difficult to anticipate in advance. However, the surveys should not be informal interviews but should follow a telephone survey protocol that allows for even open-ended questions to be easily categorized for analytic purposes.

Although the process evaluation can describe the process and suggest the initial success of the three summits and partnership development, an outcome evaluation such as that briefly outlined above will provide greater details on the true outcome of these activities.

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Appendix A
Methods Used in the Process Evaluation

The process evaluation of the SIDS summits used a combination of field observations and unstructured, informal interviews to gather data from participants and key stakeholders in the summit process. This appendix presents details of the methodology and briefly discusses the limitations of the data.

Methodology
To gather participant feedback on the SIDS summit, each meeting packet for participants contained a reaction form. Participants were asked to return the form before leaving the summit. The reaction form (appendix D) asked participants about their overall reaction to the summit and its various components; the clarity and usefulness of the information presented at the presentations and workshops and in the NICHD's SIDS resource kit; the change in their SIDS knowledge as a result of the summit; and their intentions to take the SIDS message back to their communities. The majority of questions were answered using a five-point scale, although a few open-ended questions were included. The data from the scaled questions were collated by site and across sites. The open-ended questions were used to provide additional insights into the summit process in the words of participants.

Using a field guide (appendix B), observations were made at each of the summit meetings, where informal discussions with participants took place and where workshop events were observed. These observations and discussions were captured in the evaluation report submitted after each summit, called summit site reports.

In addition, a two-month follow-up telephone interview was held with three participants from each summit. Appendix E presents the protocol for the two-month follow-up interviews. The intent of these interviews was to collect any additional comments participants had concerning the meeting after having had two months to reflect on it as well as to document relevant community activities that participants organized or implemented as a result of the summit. Project staff identified the interview respondents to provide diverse representation of the individuals participating in the summit. Each respondent represented a different location within the region, as well as a different position in the community.

In addition, informal conversations were held with NICHD staff attending the conference, and debriefings were held with the Institute staff after each summit event. Informal conversations were also held with the leadership of the host organizations, the staff of In Black Print, and the workshop facilitators for each summit. Interviews were held at various times during and after the summits. A more intensive interview was held with each of the partner organization leaders, after the completion of all three summits. Key stakeholders from the host organizations were interviewed (appendix F).

Limitations of the Study
The information gathered through the reaction forms and informal interviews with participants and summit planners provides a descriptive picture of the planning and implementation process of the summits. However, the limitations of the data, described below, must be recognized.
- The evaluation process began after planning for the summits had started, and implementation was relatively imminent. Thus, data collected on partnership development and initial planning were retrospective and relied on the memory of one or two people who were deeply involved in the process. Few written data (e.g., meeting notes, agendas, telephone conference minutes) were available, and those data did not explore some of the details that could best describe the development of the partnership. Thus, the information collected from unstructured interviews with planners could not be cross-validated with documentation data. Although reaction forms were collected following

each summit, fewer than 50 percent of all participants returned these forms. No mechanism was built into the process to follow up with participants for the purpose of encouraging them to return their reaction form. Although it is impossible to determine, it must be considered that those who did not return the forms could be particularly biased about the summits. People who are unimpressed with a meeting may not bother returning an evaluation. On the other hand, people who have no complaints also may not take the time to return the evaluation. These potential biases and the relatively low response rate suggest caution in the interpretation of the data presented.

- The evaluation design included nine interviews to be held with participants in the months following the evaluation. This information provides only a taste of what may have happened after the summits in each of the sites, but provides an opportunity for identifying potential longer-term outcome measures. Additional follow-up evaluation activities will be necessary to determine more precisely the short- and long-term outcomes of the SIDS summits.

**Appendix B
Summit Meeting Field Guide
Tuskegee, Alabama
*February 1, 2003***

1.0   Purpose

The purpose of the field guide is to primarily educate the field observers about the evaluation
approach and data collection procedures. The guide should assure the following:

- Uniformity in data gathering
- Understanding of data gathering procedures and methods
- Knowledge about the overall strategy or approach
- Information obtained from carefully crafted questions and specific topics
- Consistency in field notes
- Structure for the written report.

While the field guide cannot anticipate all conditions, the guide should inform field observers on
what to do and how to proceed as data are obtained.

Despite the rigor, there will always be room for flexibility in the gathering of data. Flexibility for
observers must always be maintained and properly balanced with informal interviews and
observation protocols. When in doubt, the field observers will contact the Task Leader as well as
seek the advice of an Evaluation Liaison (later defined).

It is important to note that the field guide will be modified and updated after each summit
meeting. This will assure that its content is appropriate and updated with changes in the
evaluation process and that these modifications are applicable to each summit meeting and the
partner organization hosting the event.

2.0   Collaborative Process

The working relationship of the partner organizations,[1] the NICHD, and the process evaluation
team[2] will function in a collaborative manner. This is akin to what is normally denoted in the
literature as a "stakeholder evaluation" process. In this process, the Task Leader will often act as
convener of these persons, when not the NICHD. In this regard, the partner organizations and the
NICHD represent the key stakeholders.[3]
The evaluation team will engage in a structured and continual effort to learn partner and NICHD
concerns, assumptions, questions, expectations, and intentions for the process evaluation. The
evaluation team will also seek to shape the process evaluation to answer partner questions and
address their priority issues. The evaluation team will remain in charge of carrying out technical

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[1] Partners are defined as the following three organizations: Alpha Kappa Alpha Sorority, Inc. (AKA),
Women in NAACP (WIN), and National Coalition of 100 Black Women (NCBW).
[2] The evaluation team from IQ Solutions is composed of the Task Leader, Dr. Abdín Noboa-Ríos, and two
consultants, Dr. Flavia Walton and Dr. Irelene Ricks. Each will work in the capacity of a field observer
when gathering data from the various summit meetings. Two persons will cover each site so that each of
the three evaluators will cover at least two summit meetings during the length of the process evaluation.
[3] Stakeholders are defined as persons who are most likely to be affected by the evaluation and whose
decisions can affect the future of the program.

research work. In addition, the evaluation team will report back to the three partners and the NICHD according to the work plan and schedule for this project to ensure the study is on target. When the data are analyzed, the evaluation team will engage representatives of the partner organizations as well as the NICHD in interpreting the findings of the case study. The optimal process for this assessment will be determined after the first summit meeting.

Since there are various representatives from the three partner organizations, the evaluation process will be structured so that there is one Evaluation Liaison (EL) from each of the three partner organizations. These three persons will work as an extension of the evaluation team to the extent possible, throughout the duration of the evaluation. In this manner, the evaluation team will primarily interface with the three ELs, one from each partner organization. The ELs, in turn, will be invited to provide: (1) input into the research process, the various instruments and protocols utilized; (2) onsite assistance at the respective summit meetings; (3) identification of key persons to interview 2 months after each summit meeting; and (4) interpretation of case study findings, and review of reports.

3.0 Field Introduction

The field observers should identify themselves as observers under a contract with the NICHD and IQ Solutions and in collaboration with the three partner organizations. Their role is to collect unbiased and systematic data about what happens at each of the three summit meetings. The data will be obtained by following prescribed standards or guiding principles of research conduct specified by the American Evaluation Association (AEA), the American Educational Research Association (AERA), the American Psychological Association (APA), and the American Anthropological Association (AAA), to cite a few. All considerations in the treatment of human subjects will also be followed, as will the respect of all persons at the site meetings.

Field observers will introduce themselves as "observers" affiliated with IQ Solutions who are collecting data by way of documenting events, interviewing people, and observing field interactions for the purpose of understanding how the partner organizations help mobilize communities in the area of SIDS outreach. Field observers are also learning to better understand how the partner organizations and the government (represented by the NICHD) work together toward a common goal, i.e., the reduction of SIDS incidence/prevalence rates in the African American community.

In the event that the observers encounter tough questions and challenges at the sites, they will respond in an accurate and succinct manner, with great candor and in a calm manner. It is important that the observers convey a message of collaboration and not create an "us" versus "them" approach. For the process evaluation to be successful, the stakeholders (including participants) should view the findings, conclusions, and recommendations as useful. The greater the collaboration, the more valid the data will be and the information will flow more naturally.

4.0 Guidelines for Conducting Observations and Unstructured Interviews

The ability to obtain good information from unstructured interview protocols is highly dependent upon how the interview protocol is structured and the questions are phrased. In the case study approach, while many of the questions will be specific, many will also be open-ended. Probing questions and techniques will be used to expand on the clarity and meaning of responses. Open-ended questions will be particularly useful when the field observer wants respondents to explain why they chose a certain answer or when the observer does not know enough to anticipate what the categories of answers might be.

Ten principles will guide the development of questions for these interviews. Some of the principles of question construction are the following.

1. Use plain language.
2. Ask only about things the respondents can be expected to know.
3. Make the question specific.
4. Define terms that are in any way unclear.
5. Avoid yes/no questions.
6. Use the working vocabulary common in the field and avoid new terms.
7. Seek second-hand opinions only when first-hand information is unavailable.
8. Maintain personal respect.
9. Be sensitive to cultural differences.
10. Be patient and courteous with difficult respondents.

The evaluation team will work with the NICHD in developing questions that are both content-specific and process-oriented. While questions will aim toward more measurable types of variables, it is also important that feelings and attitudes are adequately captured. Oftentimes, these are best obtained through open-ended questions. Many times these are impressionistic and are not easily quantifiable.

The evaluation process will rely on the unstructured approach when conducting informal conversations and interviews at the summit meetings. An unstructured interview, like a conversation, takes its own course. While the evaluator will have a strong notion of the topics to be covered, the encounter will follow a direction that can only be determined at the time of the interview. The structure interview, on the other hand, will occur as though two people were sitting down to fill out a questionnaire together. This type of interview has a definite agenda, with a set of questions to be covered and with a fixed sequence in which the questions will be asked.

Open-ended questions. The open-ended question allows for a wide range of responses. Unstructured interviews often demand an open-ended approach. We will avoid specific questions that channel people's responses to allow flexibility in response patterns and to then use probing questions to obtain greater clarity of response. Regardless of the type of question used, it is important that each question deal with only one idea or concept at a time. Typically during the informal interviews at the summit meetings, we will start with open-ended questions followed by several specific ones.

Probing questions. These are a necessary part of any interview process. They are questions that elicit additional information in the case of incomplete or vague answers. Oftentimes, the respondent will have a different frame of reference when responding to open-ended questions. The probe will assist in getting the person back on the track the evaluator would like to pursue, without derailing the process.

There is no format into which you can set probes. At times, a good way of probing is to simply reflect on what the respondent is saying by merely saying "I see" or by asking "What do you mean?" Other ways of probing are to repeat the question again, but in a different way or by repeating the respondent's reply in a summary form—again, in a reflective manner. At other times, it would be helpful to ask the respondent to explain more of their thinking by having the evaluator express more interest in the statement and asking for more explanation (or for an example).

Probes can also be conducted by focusing on one aspect of a response. Neutral questions or comments can also be used as probes, e.g., "Could you tell me more?" or "Is there anything else?" At times, it will be necessary to use questions that begin with the words why, what, or which. Throughout the interview, the aim is to obtain greater clarity from the respondent, not to box or challenge the respondent in any way.

Observational procedures. In general, these procedures fall into three categories: highly structured (systematic observation), semi-structured (anecdotal information), and unstructured (usually conducted by experts who know the subject well). Our methods will rely on a semi-structured approach, but we will also use on-the-spot checklists. For the semi-structured observations, the observers will approach the summit meetings by first determining specific information the evaluation team wants to obtain. Some of this is spelled out in the subsequent section, *Areas to be Covered by the Field Guide Process*. Other examples are the observation of participant interest and involvement in all facets of the summit meeting, also participation rates and type of engagement at the breakout sessions. The list can be extensive. It is not our intent to draw a "laundry list" of activities at this time, since these are fairly standard areas that will be observed throughout the summit meeting.

On-the-spot checklists will be used to observe what is available at the conference and how these materials or equipment are utilized. For example, if a PowerPoint presentation is taking place, what equipment is available and how is it set up? If registration is necessary, is this an efficient process and are enough folders available for everyone? We have internal checklists at IQ Solutions that can be used to assure if, in fact, standard operating procedures in conference management and logistics are being followed.

The advantage of having two field observers at each summit meeting is that the two observers can focus on different events and can cover two breakout sessions concurrently. When an event is inclusive of all participants, the observers can focus on different types of occurrences while watching the same event, such as one observer monitoring audience engagement as the other focuses on the quality and type of activity being presented (e.g., speech, slide show, activity). In addition, the two observers can later discuss their basic observations about the session and will cross-validate each other's impressions.

5.0   Sources of Data

A variety of methods will be utilized to obtain data. These primarily will be of four types: informal interviews; observations of the summit meetings; conference reaction form; and more formal followup interviews by phone.

Informal interviews. This process allows more elaborate, detailed responses obtained through qualitative techniques. An advantage is that it allows respondents to express reactions in their own language that can be critical for interpreting attitudes and feelings. The process encourages dialogue and creates greater stimulation than more formal interviews. It also allows for successive follow-ups to questions. This method will be used during the summit meetings. At times, the EL will suggest individuals for the field observer to meet. While no type of systematic sampling technique or process will be utilized, the convenient selection of participants will depend on the ability to obtain geographic variety and diversity of participant background among the participants who are willing to talk with observers.

Summit meeting observations. Trained observers can "see" what the participants who are actively involved in the summit meeting may not be able to see for themselves (e.g., conference dynamics

and overall audience response). These observations can also be highly credible when viewed as a report from a disinterested party. In addition, our field observers can provide a point of view that is different from that of people closely connected from the program and who may have a vested interest. At the same time, the ELs will know the population well and will help identify participants that might normally be missed by the observers.

Conference reaction form. This form provides immediate follow-up on participant reaction to the summit meeting. We refer to it as a "reaction form," since it quickly and efficiently records participant reactions across a group of standard questions. The form is also constructed in such a manner that it captures participant responses to their personal perceptions of knowledge obtained at the meeting as different from previous knowledge. This way, the evaluation team can gauge perceptions of the gain in knowledge as a direct result of the summit meeting. The reaction form will be available to all participants as part of the registration packet and will be turned in at the end of the summit meetings. The questions are designed in such a manner that quick, quantitative statistical tabulations can be drawn from the data collected.

The reaction form will also serve as feedback to the logistics team, as it will provide information on facilities, services, and the like. A single form will be used for conference evaluation. Development of the form represents a collaborative process between the evaluation team and the conference logistics staff.

Formal telephone interviews (post-summit). Based on the results of each summit meeting observations and unstructured interviews, telephone interviews will be held 6 to 8 weeks after the meeting with summit leaders to identify and describe different types of actions and activities that followed immediately after each summit meeting. These interviews will allow maximum opportunity for thorough examination of particular topics and predetermined aspects of field followup that may be of importance to the partners and the NICHD, depending on what has been accomplished at the summit meetings and what is expected from the field.

The interview protocol should encourage a rapport between respondent and interviewer with minimal interruption. It also allows for the opportunity to tailor the discussion to the specific conversational style (or educational level) of the respondent and strongly encourages specific and detailed responses. These interviews will also provide quick feedback, based on preliminary impressions of the observers that may provide useful or insightful information about events in the community. The telephone interview process is elaborated in the work plan. Three interviews will be conducted 2 months after each the summit meeting.

Procedures for developing questions for the telephone interviews will follow an ordered and logical sequence in construction, though the questions may be delivered using the logical flow of a casual, oral conversation. The major point is the process (how questions are introduced) and the extent of coverage (depth and variety of questions), rather than an ordered sequence.

6.0 Areas to be Covered by the Field Guide Process

Altogether, the body of observations and unstructured interviews will aim to obtain data from ten basic areas of focus. These are briefly displayed below. Each area will be accompanied by a set of questions. The queries below will form the context for the construction of specific questions that will be asked in the field. In general, these ten areas will form the database from which case studies will be constructed.

1. **Conceptual Framework**—*What drives the summit meetings and the approach?*
   - What are the underpinning assumptions about the campaign?
   - Is there evidence of effectiveness from past efforts?
   - What constitutes best practice?

2. **Goals of the Summit Meetings**—*What do the summit meetings hope to accomplish?*
   - If successful, what are the expected outcomes?
   - What is the content, process, and purpose of the summit meetings?
   - What exactly occurred at the event?
   - How did participants feel about the process?
   - How can effects be measured?
   - Did the activities clarify the mission of the initiative? Were the goals clear?
   - Do participants now know what to do?

3. **Strategy and Approach**—*What is the overall strategy and approach at the summit meeting?*
   - How does the approach reinforce and complement goals of the initiative?
   - How does planning take place?
   - What is the infrastructure to support the activities?

4. **Materials/Resources**—*What materials, products, and resources are used?*
   - Are materials being prepared for distribution, presentation, and training?
   - What resources are available to support community activities?
   - What is the type and quality of information provided?
   - What is the relevancy and utility of the materials and products?
   - Are the materials helpful? How?
   - How are materials going to be used?

5. **Selection Process**—*What is the selection process?*
   - Who are the participants attending each summit meeting?
   - How were partners selected?
   - Who are the partners?
   - Identify the partners/organizations (e.g., How long have they been organized? What is their mission? What is their governance, and size? Where are they located? Who are their affiliates? What are their programs?)

6. **Partner Roles and Relationships**—*How do partners relate to the affected communities?*
   - What is the relationship among the three partner organizations and the NICHD? In what capacity? How do they work together?
   - Are there other partners and stakeholders created from this process? How?
   - Have there been similar ventures prior to this initiative?
   - How do conference participants relate to their communities?
   - To what extent is the process a catalytic agent for change? What is the evidence?
   - Are formal (e.g., funding contracts) or informal agreements (e.g., other supporting mechanisms) emanating from this initiative? At what levels? With what funds? Toward what ends?

7. **Involvement with SIDS Initiatives**—*What is the nature of past involvement?*
   - How did your organization get involved in the SIDS outreach campaign?
   - Identify previous organization experience with SIDS or SIDS-related projects?
   - How did the project come to the attention of your organization (or local units)?

8. **Implementation/Application**—*As a result of the summit, how are activities being carried out?*
   - Who is carrying out the activities?
   - What project activities are being implemented at the site?
   - What is the level of adaptability/flexibility of outreach efforts?
   - Who is in charge? What is the project oversight? Is there an advisory group?
   - How will voluntary participation by organizational entities be accomplished?
   - Will there be training for other participants?
   - How is the target population identified?
   - What is the depth of penetration (e.g., level of grassroots participation, level of partnerships, networks)?

9. **Evaluation of the Initiatives**—*How will the evaluation be used? What role does it play?*
   - Are there internal (organization level) assessment procedures?
   - What about the larger impact evaluation at a later time?
   - How are best practices being defined?

10. **Next Steps**—*What happens after the summit meeting?*
   - What is the level of follow-up?
   - How is accountability created?
   - What is the commitment to continue?
   - Are there plans for sustainability (e.g., future funding)?

Appendix C
Summit Observations and Informal Discussions Guide

Altogether, the body of these observations and unstructured interviews aim to obtain data from different areas of focus. These are briefly indicated below. Each area is accompanied by suggested questions. The queries help guide the focus of the observations and assist in formulating probing questions with participants, as the situation arises. In general, these areas will help construct key information from which case studies will be constructed.

1. **Conceptual Framework**—*What drives the summit meetings and the approach?*
    *   What are the underpinning assumptions about the campaign?
    *   What makes this summit focus different from all others?
    *   Is there evidence of effectiveness from past efforts?
    *   What is being perceive as best practice?

2. **Goals of the Summit Meetings**—*What do the summit meetings hope to accomplish?*
    *   If successful, what are the expected outcomes?
    *   To what extent are these verbalized and spelled out to the audience?
    *   What is the content, process, and purpose of the summit meetings?
    *   How does the agenda/process complement (or compete) with these purposes?
    *   What exactly occurred at the event?
    *   How did participants feel about the process and content?
    *   How can effects be best inferred from participants can? Can they be later measured?
    *   How do the activities clarify the mission of the initiative? How clear are the goals?
    *   Do participants now know what to do after the summit?

3. **Strategy and Approach**—*What is the overall strategy and approach at the summit meeting?*
    *   How does the approach reinforce and complement the goals of the SIDS initiative?
    *   How did planning for the summit take place? Who was involved? How was information communicated to the field?
    *   What is the infrastructure to support the activities?
    *   Were advanced meetings/conference calls held? To what purpose? Who was involved?
    *   What is the role of In Black Print?

4. **Materials/Resources**—*What materials, products, and resources are used?*
    *   Are materials being prepared for distribution, presentation, and training?
    *   What resources are available to support community activities?
    *   What is the type and quality of information provided at the meeting?
    *   How do the workshops reinforce the process? Who participates at these?
    *   What is the relevance and utility of the materials and products distributed?
    *   Are the materials helpful? How?
    *   How are participants going to use these materials?

5. **Selection Process**—*What is the selection process?*
    *   Who are the participants attending the summit meeting?
    *   How were sites/cities and bus captains selected?
    *   How was information disseminated?
    *   What partners became involved?

- To what extent did all sectors of the community feel included?
- How diverse is the audience?
- How does the selection process tap into other networks?
- Describe the partnership and local organizational involvement (e.g., How long have they been organized? What is their mission, governance, and size? Where are they located? Who are their affiliates? What are their programs?)

6. **Partner Roles and Relationships**—*How do partners relate to the affected communities?*
   - What is the role of the NICHD with the partner organization and the summit? How do they work together? In what capacity?
   - Is this different from other summits?
   - How does leadership and the summit meeting tie to the logistics role of conference management?
   - To what degree are other partners and stakeholders involved? How?
   - Have there been precursors or antecedent activities prior to this initiative?
   - How do conference participants relate to their communities?
   - What communities are represented? Who is present? From where? At what level?
   - To what extent is the process a catalyst for change? What is the evidence?
   - Are formal (e.g., funding contracts) or informal agreements (e.g., other supporting mechanisms) emanating from this initiative? At what levels? With what funds? Toward what ends?
   - Were additional funds sought from other means?
   - How are partners relating to each other and to In Black Print?

7. **Involvement with SIDS Initiatives**—*What is the nature of past involvement?*
   - How did your organization get involved in the SIDS outreach campaign? How did the participants get involved?
   - What are the previous organizational experiences with SIDS or SIDS-related projects?
   - How did the meeting come to the attention of local organizations (or local units)? Who played key roles?

8. **Implementation/Application**—*As a result of the summit, how are activities being carried out?*
   - Who is carrying out the activities?
   - What project activities are being implemented at the site?
   - What is the level of adaptability/flexibility of outreach efforts?
   - Who is in charge? What is the project oversight? Is there an advisory group?
   - How will voluntary participation by organizational entities be accomplished?
   - Will there be training for other participants?
   - How is the target population identified?
   - What is the depth of penetration (e.g., level of grassroots participation; level of partnerships; and networks)?

9. **Internal Evaluation of the Initiative**—*Will any evaluation take place? How? What role does it play?*
   - Are there internal (organization level) assessment procedures?
   - Is there organizational feedback? Of what type?

- How are activities being managed by the organization? For example, is this centralized or decentralized? Are criteria pre-established? Who decides and how are decisions being made?
- Will participant feedback be sought at a later time, such as through bus captains?
- How are best practices being defined, if at all?
- How is the partner organization learning from past events? Past summits?
- Does the organization seek advice? How? From whom?

10. **Follow-up**—*What happens after the summit?*
- What is the level of follow-up?
- How is accountability created?
- What is the commitment to continue?
- Are there plans for sustainability?
- How will later communication occur?

Appendix D
Summit Meeting Reaction Form
City, State
Date

Please circle the best answer to the following questions:

1. **How satisfied are you with this summit meeting?**

    Not Satisfied   1   2   3   4   5   Very Satisfied

2. **How helpful is the information that was presented?**

    Not Helpful   1   2   3   4   5   Very Helpful

3. **How helpful were the SIDS resource kits?**

    Not Helpful   1   2   3   4   5   Very Helpful

4. **How would you rate the conference facilities/services?**

    Poor   1   2   3   4   5   Excellent

5. **Overall, how knowledgeable were the speakers about the topics presented?**

    Not Knowledgeable   1   2   3   4   5   Very Knowledgeable

6. **How clear and understandable was the information presented?**

    Not Clear   1   2   3   4   5   Very Clear

7. **How clear are you about how to carry out community outreach?**

    Not Clear   1   2   3   4   5   Very Clear

8. **How clear are you about how to use the information you received at this summit meeting?**

    Not Clear   1   2   3   4   5   Very Clear

9. **What is your comfort level regarding how to use the SIDS resource kits?**

    Not Comfortable   1   2   3   4   5   Very Comfortable

10. **How knowledgeable were you about SIDS community outreach before and after the meeting?**

    Before: Low Knowledge   1   2   3   4   5   High Knowledge

    After: Low Knowledge   1   2   3   4   5   High Knowledge

11. **How culturally sensitive were the meeting presentations and activities?**

    Not Sensitive   1   2   3   4   5   Very Sensitive

12. **What next steps will you take when you return to your community? (Please check only those that apply.)**

- " Use the resource kits to give presentations about SIDS
- " Hand out materials from the resource kits
- " Talk with friends and neighbors about SIDS
- " Meet with community leaders about SIDS
- " Other (specify _____)

13. **Which sessions were *most* helpful?** _____

    Which sessions were *least* helpful? _____

    Please explain. _____

    _____

14. **How can a meeting of this type be improved in the future?**

    a)_____

    b)_____

15. **Is there anything else you would have liked this summit meeting to cover?**

    _____

16. **Other comments:** _____

    _____

Have you ever attended a meeting, conference, or workshop on the topic of SIDS before this summit meeting?

    " Yes   " No

If "yes," please answer the following questions:

When did the previous meeting, conference, or workshop take place?

    " During the past year   " About 1 to 3 years ago   " Over 3 years ago

How long was the previous meeting, conference, or workshop?

    " 4 hours or less   " 1 day   " 2 days   " 3 days or more

How helpful was this summit meeting compared with previous meetings, conferences, or workshops on SIDS?

    " This summit meeting was *more* helpful.
    " This summit meeting was about the *same*.
    " This summit meeting was *less* helpful.

Appendix E
Follow-up Telephone Interview Questionnaire 2 Months After Each Summit Meeting

1. Did you participate in the entire summit meeting? Which events?

2. How prepared to work in your community (or back home) did you feel after the summit? How prepared do you feel now?

3. What is the difference between what you thought you were going to do in your community after the summit and what you have actually accomplished?

4. Have you conducted activities (or participated in SIDS activities) since the summit? [Alternative question: Have you had a chance to work with a local community on SIDS since the summit? What have been some of your experiences, if any? What are some of your accomplishments?]

5. In general, have you encountered any challenges in communicating to others about SIDS?

6. What are your next steps in the process of communicating to others about SIDS?

7. Do you know about others who attended the conference with you? What activities are they doing regarding SIDS? Are you in touch with them? Do you work with them in any way?

8. Have any of the sponsoring organizations (AKA, NCBW, or WIN) been involved in your SIDS work? In what ways?

9. If you were to think back on the summit, what might you now add to the event that would have prepared you better to talk about SIDS? In the same vein, what would you suggest to improve the program at future summit meetings or similar events?

Appendix F
Stakeholder Interview Protocol
(post-summits)

Introduction: The purpose of the interview is for reflection and insight.

It would be good to find out more about (a) the background that led to the SIDS summit meetings; (b) accomplishments as a result of the meetings; and (c) implications for the future.

Protocol

1. **Tell us a little bit about how the summit meetings came into being.**
    Prompt:

    a)   How did the coordination end up being among the three female organizations—WIN, NCBW, and AKA?

    b)   Why was there a decision to have regional meetings versus other types of outreach? Was this a conscious decision with expected results? What may have happened if the order of the place of the meeting was reversed, with Tuskegee coming at the end?

    c)   How was the decision made to begin in Tuskegee, then Los Angeles and Detroit?

    d)   Is this the first time your organization worked with the federal government? The NICHD? If yes to both, was there a difference?

    e)   What would you suggest for federal agencies in working with grassroots organizations?

2. **In your opinion, what was the primary objective of the summit meetings?**

    a)   To what extent do you think this was successful?

    b)   What could planners of the summit have done differently?

3. **To what extent do you feel the major objectives were met?**

4. **How did your organization do things different from and similar to (or complementary to) the other partners?**

5. **In retrospect, what should your organization have done differently? Why?**

6. **While the summits are hard to compare, how would you characterize each of them?**

    Prompt:
    a)   Among the summits, which ONE do you feel had the MOST immediate impact on participants?

    b)   Was the design of the regional summit meetings to build on each other or was that just an independent result of the process?

7. **Do you believe the impact of the summits will be long-term and sustainable?**

    Prompt:
    a)   To what extent should the NICHD need to be involved to sustain the momentum?

    b)   In what others ways can the NICHD reinforce field efforts by African American grassroots organizations?

8. **From your vantage point, has the NICHD ever done something like this in the past? If no, might this set a new precedent? If it sets a new precedent, what would you advise the government to do differently? [Or what would you suggest for the government/NICHD to do better in the future, especially as it regards their role?]**

9. **What are some of the next steps to continue the SIDS momentum? What will your organization do in the area of SIDS?**

    Prompt:
    a)   What would be the most helpful?

    b)   Are other regional meetings being planned?

    c)   How about a national meeting 1 year later?

    d)   Is there interest in bringing in other groups beyond the initial three organizations?

10. Do you perceive the meetings on SIDS to have an effect on other minority illnesses in the future? In what ways?

11. Does your organization plan to network with other federal agencies (e.g., the Office of Minority Health, the Maternal and Child Health Bureau of the Health Resources and Services Administration) on research and services impacting SIDS and other minority health issues?

12. How do the SIDS events tie into other health priorities for your organization?

Prompt:
    a)   Does your organization have other SIDS initiatives/plans for the future?

    b)   Is SIDS a model for future work at the grassroots level?

Appendix G
Partnership for Reducing the Risks of SIDS
in African American Communities: A Process Evaluation Model

Social Context	Partnership Coalition Development	Operational Strategy	Summit Short-Term Outcomes	Longer-Term Outcomes

Organization Environment

- **Health/SIDS Disparities**
- Perceptions of health and well-being
- Perceptions of SIDS in African American communities

- **National Organizations**
- Missions
- Leadership
- Relationships

- **NICHD**
- Mission
- Leadership
- Relationships
- Public health campaigns

Development of Shared Vision

- Process: Hold formal and informal meetings to develop vision and direction
- Outcomes: Develop overall goals and strategy

Partnership Formation

- Secure buy-in and commitment to partnership
- Agree on roles and responsibilities

Organizational Structure

- Establish organizational procedures
- Create a shared decisionmaking process
- Develop a meeting contract and statement of work
- Develop communication procedures

Summit Meeting Process

1. Planning
2. Publicity
3. Summit Agenda
4. Implementation
5. Assessment
6. Provide feedback; build on lessons learned; and refine strategy

Intended Target Audiences

- Health care institutions (e.g., hospitals, clinics)
- Health care professionals
- State and local governments
- Faith communities
- Community-based organizations
- Individuals

Planned Activities

- Conduct SIDS reduction workshops in the community

Spin-off Events/Activities

- Other summits (local, state)
- New partnerships
- Sponsorship/funding of related infant and child health events

Government-Community Collaborations

- Reflections from stakeholders and participants
- Continued collaborative efforts
- Replication of collaborative model
- Additional local partners working on SIDS

Changes in Knowledge, Attitudes, and Behaviors of Summit Participants

- Documented SIDS prevention activities at regional, state, and local levels
- Change in mortality statistics

Evaluation