Building Integrated Systems to Address Sudden Unexpected Infant Death

S P R I N G   2 0 0 7

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The Changing Landscape of Sudden Unexpected Infant Death

In 1969, the term Sudden Infant Death Syndrome (SIDS) was proposed to describe a clinical entity with characteristic findings to diagnose the sudden unexplained deaths of infants, typically during their sleep. At this point in time, the role of organizations formed by families was to support families in their losses and to advocate for research to address this terrible problem. In 1974, federal legislation was passed to fund that research and to establish programs to provide information and counseling to families following a SIDS death. A series of state programs through Title V Maternal and Child Health (MCH) agencies were founded to meet this purpose. In 1992, with the recognition that placing an infant on his/her back to sleep could significantly reduce the risk of SIDS, both family support and advocacy organizations and state SIDS programs expanded their efforts to address disseminating this key public health message. In these early years, the number of entities addressing SIDS and the core missions were relatively small and the message clear and seemingly easily communicated.

In 2007, the picture is very different. Ongoing research and the institution, in many jurisdictions, of death scene investigations have led to a far more complex set of risk factors and protective factors and a set of diagnostic issues that broadened the discussion from the one diagnosis—SIDS—to a more differentiated approach to diagnosis of sudden unexpected deaths of infants (SUID). At the same time, through private sector and government efforts, multiple initiatives to address infant mortality and racial and ethnic disparities in these mortality rates have created a larger and more complex set of players addressing the issue. Finally, as the number of SIDS diagnosed deaths has decreased, diminished funding for state SIDS programs and a diminished sense of urgency that spurred the original efforts have led, in many states, to greatly diminished public health resources dedicated to supporting families after a loss and SIDS specific risk reduction efforts.

New Understanding of Sudden Unexpected Infant Death

In the past almost 40 years, research has identified a range of findings that must be addressed today. These findings, which were used to inform the 2005 American Academy of Pediatrics policy on risk reduction include:

- racial and ethnic disparities in infant mortality rates and in adoption of behaviors to reduce risks for sudden and unexpected deaths;

- leveling of the decrease in SIDS deaths and a concomitant increase in other causes of unexpected infant death;

- identification of non-sleep position risk factors including smoking, alcohol use, overheating and protective factors including use of pacifiers that are complex and not easily communicated or accepted in some communities;

- identification of multiple sleep related risk and protective factors beyond "Back to Sleep" that are not easily communicated or accepted by some constituencies;

- genetic risk factors;

- research that may lead to screening for risk based on neurobiological findings.

(Sudden Infant Death Syndrome Task Force, 2005; Weese-Mayer, et.al., 2007; Paterson, et.al., 2006)

In addition, research has shed light on how and if messages related to risk reduction are being delivered and accepted. The assumption had been made that families were receiving a consistent message from multiple health systems providers and were incorporating those suggestions in their behaviors. The initial

and dramatic drop in SIDS rates following the institution of the Back to Sleep Campaign may have supported that confidence. As rates leveled out, a more complex picture emerged. Families reported never having received the messages and not necessarily heeding recommendations of health care providers, but rather listening to older, more experienced women in their communities who did not endorse back sleeping. The importance of cultural and linguistic competence to address risk reduction strategies and the importance of engaging diverse communities is more salient than ever. Newborn and intensive care nurseries were not consistently following safe sleep recommendations and not teaching them to new parents. The need to look across the systems and communities that support new parents becomes critical at the same time that the message has become more complex. (Rao, et.al., 2006; Colson, et.al., 2006; Bullock, et.al., 2004; Colson and Cohen, 2002; Peek, et.al., 1999; Stastny, et.al., 2004; Willinger, et.al., 2000)

New Partners and Stakeholders

As the understanding of sudden unexpected infant death has expanded, so has the number of programs and initiatives designed to address infant mortality rates and disparities. To name just a few federal efforts and federally promoted models that are executed at the state and local level are the following:

• Healthy Start;

• Closing the Gap on Infant Mortality;

• NICHD Back to Sleep African American Outreach initiative;

• NICHD Healthy Native Babies project;

• Fetal and Infant Mortality Review teams;

• Child Death Review teams with a public health focus; and

• Center for Disease Control and Prevention Sudden Unexpected Death Scene Investigation form and training.

In addition, campaigns to address smoking during pregnancy have grown and community-based and national racial and ethnic specific organizations have highlighted and instituted programs to address disparities in infant mortality. March of Dimes has focused on the issue of prematurity, a significant risk factor in infant death. And in each state and locality, an array of responses to infant mortality has grown. At the same time, national and regional private sector support and advocacy organizations including First Candle/SIDS Alliance and the C.J. Foundation for SIDS continue their steadfast efforts. There are strong leaders in the organization for professionals who address SUID in the Association of SIDS and Infant Mortality Programs. There is an array of potential resources (fiscal, human and knowledge), many champions for this issue, but too many opportunities for fragmentation, overlapping efforts, competing messages, and too many opportunities for uncoordinated efforts to fail.

At the same time, many state SIDS and Infant Death Programs are losing resources and staffing time to address the complex, multifaceted issue of SUID. SIDS Project IMPACT completed a telephone inquiry of state SIDS programs in 2005-2006. Data was collected from the state Title V SIDS and Infant Death Program administrators (or the designee responsible for SIDS/ID) in the fifty states and the District of Columbia. Programs reporting indicated that in the last 3 years 53% had level funding and a full third (33%) had a decrease in funding. Eighty-two percent (41/50) described a need for more financial support, including 10 percent (5/50) who specifically mentioned the need for support from Title V.

Shifting the Paradigm to Address SUID

Throughout the human services field, there has been a paradigmatic shift over the past 30 years when addressing complex issues in an environment of shifting or diminished resources.

The creation of coordinated, integrated systems has been the focus of multiple efforts in the Maternal and Child Health Bureau (MCHB), Health Services and Resources Administration (HRSA), U. S. Department of Health and Human Services. Beginning in the late 1980s the Division of Services for Children with Special Health Care Needs promoted integrated systems approaches (Bronheim, et.al.1996) and this was institutionalized in the OBRA '89 legislation. The role of state Title V programs for children and youth with special health care needs was transformed from service delivery to individual children and families to systems development. MCHB has also promoted systems integration for services and supports for young children (Halfon, et.al. 2004) and their families. In other arenas, the Substance Abuse and Mental Health Services Administration promotes systems integration for serving children and youth with severe emotional and behavioral problems (Stroul, and Friedman, 1996) and substance abuse.

Addressing sudden unexpected deaths of infants is the kind of complex issue with multiple constituencies and programs that is now ripe for a systems integration approach. MCHB has promoted states' addressing SIDS and other infant death issues in state level programs. It now seems the moment to reconceptualize those efforts from providing services and promoting risk reduction, to leading or partnering with other leadership to create a systems approach.

This systems paradigm entails creating the relationships, an infrastructure and a process to bring together the complex network of stakeholders, including voices from communities disproportionately affected by sudden unexpected infant deaths. The goal is to create integrated, consistently resourced and culturally and linguistically competent approaches to meet *Healthy People 2010* Goal 16 to reduce infant and fetal mortality. These approaches must have buy-in and be evaluated at all levels of the system—individual families, communities, organizations/agencies focused on infant mortality, organizations that touch the lives of families with infants and young children, larger health systems players including birthing hospitals, health plans, and policy makers.

The assets of state SIDS and Infant Death programs, with their history of addressing both bereavement support and risk reduction, and the expertise and wisdom of the professionals in those programs should not be redirected. These programs, in many states, are uniquely positioned to utilize or create partnerships to lead a shift from direct service delivery and risk reduction education to creating integrated systems to address SUID.

Learning From One State's Journey

The remainder of this report provides a narrative of the Michigan SIDS program—Tomorrow's Child/Michigan SIDS—a journey from 25 years of parallel and uncoordinated efforts to a new, state-wide integrated systems approach to addressing SUID. It illustrates the program's experiences traversing the continuum of systems development. It demonstrates how concepts such as private/public partnership, well designed strategic planning processes and increasing engagement of stakeholders, especially the communities most impacted by SUID, led to the creation of a system that is statewide, well-resourced, and addresses cultural and linguistic competence. This story was written by Tomorrow's Child/Michigan SIDS as a way to share their experiences and to make abstract concepts real. The National Center for Cultural Competence (NCCC) has contributed to the framework of the overall report and helped formulate the section on cultural and linguistic competence.

The Michigan story is told in three sections that follow. First, the story tells of the journey from a set of parallel private and public responses to SIDS to an integrated system. The second section addressing the issue of resources—in a time of shrinking resources for public health initiatives it is useful to learn about the strategies for fundraising that have support the system in Michigan. Finally, the third section highlights the ways in which Michigan utilized culturally and linguistically competent approaches in building a statewide system.

Systems Integration: The Michigan SIDS Program and Infant Safe Sleep

DEDICATION: *To the legacy of SIDS families and professionals*

What is Michigan's Integrated System?

Michigan has endorsed Infant Safe Sleep policies. Government endorsement and statewide support for this new, broad set of recommendations is a remarkable accomplishment in which public, private and nonprofit organizations worked together toward a common goal: reducing infant deaths related to unsafe sleep practices. Working within a growing, integrated system of stakeholders, a broad-based workgroup crafted an Infant Safe Sleep Final Report that has driven the changes in Michigan. However, creating the infrastructure, building trust, enhancing communication and sharing resources that led to the current system began almost thirty years earlier. The current system is well resourced and works to create and sustain culturally and linguistically competent approaches to systems building and to services and supports to families and communities.

Michigan's Infant Safe Sleep Campaign is aimed at changing behavior and creating an environment that reinforces sustained adoption of these changes. The overarching theme is permanent systems change through rules, policies, standards, and procedures. The recommendations reach across existing systems and involve the public and private sectors to provide a consistent message among state agencies, healthcare and non-traditional partners. Infant Safe Sleep has partners and champions outside the traditional public health and medical models. The Michigan Department of Human Services, Department of Education, social services, child welfare, law enforcement, child care, parent education and local communities were among the entities rallying for a cohesive Infant Safe Sleep effort. However, not everyone initially supported Infant Safe Sleep; nutrition and breastfeeding programs were concerned that safe sleep might have a negative impact on the mother's decision to nurse her baby. Utilizing an effective partnership and systems building process, current components of the integrated system to address Infant Safe Sleep include:

• state health and human service agencies;
• state and local education agencies;
• academics;
• mortality review teams;
• pediatricians;
• childcare agencies and providers;
• local communities;
• breastfeeding advocates;
• birthing hospitals;
• health plans and;
• Tomorrow's Child/Michigan SIDS.

Michigan's Infant Safe Sleep Campaign is envisioned as a private/public partnership coming from an integrated, state-wide system. From the public perspective, state departments are integrating the Infant Safe Sleep message into existing programs and services. Distribution of Infant Safe Sleep materials and training continue throughout the state agencies that provide services to pregnant women, infants, and their caregivers. The state is

designing a new Safe Sleep logo, website and online professional training modules.

The private sector is responding by sharing responsibility for and committing resources to Infant Safe Sleep. Tomorrow's Child/Michigan SIDS (the private, non-profit organization that now runs the Michigan SIDS program) is integrating fund development with programs and is able to engage new public/private partners to support Infant Safe Sleep through grants, donations, event sponsorship, matching funds and in-kind donations.

The broad-based systems approach, which engaged the governor, led to partnerships to assure adequate resources for the initiatives. Initial funding was provided through the state health department which persuaded the legislature to appropriate one million dollars to address disparity in infant mortality rates. Two hundred and fifty thousand dollars was allocated to implementing the Infant Safe Sleep Final Report. Tomorrow's Child/Michigan SIDS served as the fiduciary seat of the project and thus was able to leverage the funds to secure additional grants and fundraising opportunities to support Infant Safe Sleep.

Part of the governance structure, an Oversight Committee, provided input on the interventions. This group determined that interventions be culturally appropriate and implemented in communities with the highest infant mortality disparity rates. Initiatives are data driven with evaluation as a key component. Projects include standardized safe sleep materials, focus groups with the target populations, and institutionalizing safe sleep in hospitals, health plans, and childcare.

Challenges of Building an Integrated System to Address SUID

Building a state-wide, systems approach to reducing SUID rates and disparities is not an overnight event. It results from enlightened and effective leaders who can articulate and share a new vision for integrating all the key players in reaching goals to reduce infant mortality and sparing families the heartache of losing an infant. It is also built on a solid foundation of experiences of previous partnership, increasing trust among the system members, and the public will to address the issues. Moreover, it requires the time and a focused process to develop the shared understanding of the issues, definitions of challenges, and identification of resources within a context that tolerates and addresses conflicting views and interests. Such a process can then lead to the creation of a systems approach that is implemented and evaluated by an ongoing, institutionalized, collaborative structure. Evidence and data guide the actions and are used to monitor fidelity to the chosen models of action and provide input for improving efforts.

Systems Development Continuum

Numerous models characterize the changing nature of relationships among potential partners in systems development, but Himmelman (1992) presents a useful framework. It outlines a series of steps that lead from isolation and parallel efforts to collaboration.

Steps in Collaboration

Networking—exchanging information for mutual benefit with an informal relationship and beginning trust.

Coordinating—exchanging information and altering activities for mutual benefit to achieve a common purpose with higher levels of relationship and trust.

Cooperating—in addition to altering activities, this stage involves sharing resources to achieve a

common purpose and may involve formal agreements and high levels of trust and time together.

Collaborating—in addition to the previously noted activities, collaborating groups work to enhance the capacity of the others involved and the groups share risks, responsibilities and rewards.

(Himmelman, 1992)

This report reflects one step beyond Himmelman's final step of collaboration to a broad sustainable transformation that creates a new entity—an integrated system. In systems integration collaborating partners create and formalize a new infrastructure to provide leadership, governance and accountability to the combined efforts in order to institutionalize shared goals.

The Michigan Transformation Journey

Tomorrow's Child/Michigan SIDS began as a parent nonprofit organization which was ultimately awarded the contract for the state SIDS program. In its current configuration, the governance and function of Tomorrow's Child and the Michigan SIDS/SUID program have become integrated. The resulting organization is different from many state SIDS programs that provide direct bereavement support and risk reduction services. The Michigan model approaches SIDS/SUID from a systems change perspective with Tomorrow's Child/Michigan SIDS providing infrastructure, convening groups, garnering resources and advocating for the cause. The evolution from direct service to systems change was gradual and details and lessons learned from the Michigan journey may be useful for other states. The process moved along a continuum from parallel efforts to systems integration, starting with the response of the public and private sector to the proposed SIDS diagnosis in 1969.

Response to the New SIDS Diagnosis— Parallel Efforts

When the term sudden infant death syndrome (SIDS) was proposed in 1969, families who had experienced the sudden unexplained death of an infant were the motivating factor behind the recognition of SIDS as the most significant cause of post neonatal death. The early challenges for private sector family support and advocacy groups were raising awareness about the magnitude of the problem and convincing professionals and the public that parents were not to blame for their infant's death.

In the public arena the Sudden Infant Death Syndrome Act, P.L. 93-270, passed by the U.S. Congress in 1974, authorized funding for research and for programs to serve families who had lost an infant. In 1975, Wayne County, Michigan was selected for a federally funded SIDS counseling and education demonstration program. After being hosted in several venues the program was moved to Children's Hospital of Michigan in anticipation of the federal block grant program. At that time, 4 additional counties with the next highest SIDS rates were given grants to operate SIDS programs. After several more changes, the program ultimately was housed in the Detroit Regional Office for Children's Special Health Care Services.

In this early phase, the parent driven response and the public response were isolated, parallel efforts. SIDS parents clustered together offering support and consolation to each other. Local public SIDS programs were led by professionals who defined policies and interventions, and provided direct services to bereaved families. At the state level, public and private services were not coordinated, communication and linkages between the parent and state SIDS program were informal.

Early Systems Change in the Michigan SIDS Program

Structural changes in the parent organization and state SIDS program initiated Michigan's movement along the continuum of systems integration. Over the years, the isolated SIDS families had coalesced into regional chapters with boards of directors and individual fundraising events. The parent chapters merged to form one state organization, Tomorrow's Child, a step that strengthen their decision-making, encouraged coordination of services, broadened fundraising, and united advocacy efforts.

Tomorrow's Child's attentiveness to corporate infrastructure and governance provided the backbone for future collaboration, fundraising and systems integration. Early in its development, the parent organization hired a nonprofit management professional who broadened the Board of Directors to include families as well as state policymakers and infant mortality organizations. The Board chartered the parent organization as a nonprofit corporation and obtained IRC 501 (c) (3) designation which provided the base for sustainable SIDS initiatives.

The formation of Tomorrow's Child also had an impact on the structure of the state SIDS program. At the urging of the parent organization, the state health department consolidated the numerous local SIDS grants into one statewide SIDS program. Resultant systems changes included:

• state leadership for the SIDS program;

• centralized state decision-making and communication;

• expansion and better coordination of statewide services;

• clearer definition of private and public roles;

• raised awareness of SIDS at the state level; and

• improved surveillance of SIDS deaths.
With a cohesive parent nonprofit corporation and a centralized state SIDS program, a framework was provided for inter-organizational linkages and communication. After twenty five years of functioning on parallel tracks, Tomorrow's Child and the Michigan SIDS program began to exchange information about how each could support bereaved families, improve provider and responder training, and enhance better understanding of sudden infant death syndrome.

Back to Sleep Provides New Opportunities to Advance Systems Changes

At the point at which Back to Sleep was launched, Tomorrow's Child and the Michigan SIDS program had entered the phase of networking and communication on service issues. The parent organization, Tomorrow's Child, was encouraged to move forward with the Back to Sleep campaign by health professionals who were aware of the impending national campaign. Using community coalition building strategies, Tomorrow's Child convened a broad-based committee—a coalition of key stakeholders—consisting of public health nurses, apnea experts, physicians, providers, health and human service professionals, and families to design the first Back to Sleep materials and develop a campaign to communicate the message. The efforts were underwritten by private funds.

The private and public sector brought unique strengths to the Back to Sleep campaign. The benefit of having the nonprofit organization take the lead in the early stages of Back to Sleep was that it was not confined by bureaucracy, changes in political administration or funding limitations. Because of its independence, the private sector could also advocate for government action on Back to Sleep. On the other hand, the public sector could provide credibility and authority needed to sustain the new initiative. As Tomorrow's Child moved from developing Back to Sleep materials into implementation, it sought a more formal linkage with the state health department thereby taking another forward step on the continuum of systems development.

Strategies for engaging government agencies are widely varied and, to be successful, should take into account the specific politics and personalities involved. Examples might include legislative mandate or administrative rules. In Michigan, past experience suggested that a task

force might succeed. Tomorrow's Child, representing the families and the original Back to Sleep committee, advocated with the state health department and the Director of Maternal and Child Health (MCH) for a Task Force to address Back to Sleep. The MCH director responded by convening a statewide SIDS Task Force and justified the action, in part, on the lack of culturally competent services in relations to SIDS.

An Infrastructure for Systems Change
The Michigan SIDS Task Force established the infrastructure for further systems change in the SIDS program. Building a coalition (in this case a SIDS Task Force) of key stakeholders is critical to the systems change process. (Agranoff, 1991) Participants in the coalition must include individuals who have the authority to commit their organizations and resources to the initiative. The MCH Director at that time provided the vision and leadership required to select and engage these key stakeholders. She also created a formal process to assess needs, identify the priorities and define the outcomes. In its final structure, the Michigan SIDS Task Force was broadly representative and included provider groups that were involved in SIDS, state agencies, the SIDS family support community (not yet fully representative of the communities most impacted), medical examiners, and other stakeholders.

In the systems change model, coordination is a crucial stage in change strategy. The Michigan SIDS Task Force provided succinct recommendations that required coordination including:

• clear definition of roles and responsibilities;

• more formal communication between Tomorrow's Child and the state SIDS program;

• improved organizational linkages between the private and public organizations;

• expanded ownership for the SIDS program outside state government; and

• specific recommendations for private and public activities.

Public funding for the Michigan SIDS Task Force recommendations did not increase. However, a more trusting relationship developed between the state health department and Tomorrow's Child. In addition to shared goals, there began a sharing of resources. Tomorrow's Child agreed to assist in underwriting the Task Force Final Report and to continue funding for the Michigan Back to Sleep materials. Back to Sleep materials created by Tomorrow's Child bore the health department logo and statement "in partnership".

Impact on the Private Sector
The state had responded to Back to Sleep by building a sustainable infrastructure for the Michigan SIDS program that addressed risk reduction activities, SIDS grief services and surveillance of infant deaths. The redefined SIDS program called for coordinated efforts between the private and public sectors.

The Back to Sleep campaign and the increasing responsibilities for the campaign propelled comparable structural growth for Tomorrow's Child. The Board of Directors underwent a strategic planning session to change the direction of the organization. Efforts were made to create formal connections between the private nonprofit organization and the state SIDS program. In addition, the first development professional was hired to assure a consistent revenue base. These changes in governance, the initial steps to integrate Tomorrow's Child and the state SIDS program, and attention to fund development, deepened the private sector infrastructure to help support and carry out the next step in the private/public partnership— formal collaboration.

Overview of Strategic Planning

What is strategic planning?
Strategic planning is a step-by-step process to help an organization adjust to changing environments, transform and revitalize, focus energy, and ensure members are working toward the same goals. It is a disciplined effort to make fundamental decisions and take action that shape and guide what an organization is, what it does, why it does it with a focus on the future (Bryson, 2004).

Who should be involved?
The board and staff share responsibility for strategic planning and must carefully decide who will be involved. As a general rule, the process should involve important stakeholder groups.

When is the time right?
Each organization must decide for itself when the time is right to plan strategically. New opportunities, loss of funding, mission shift, and leadership changes are often the impetus to plan (Lyddon, 1999).

How does planning work?
A professional consultant can provide structure to the activities, facilitate consensus, and keep the process and discussions on track and on time. Board and staff often lack objectivity and time to oversee strategic planning. Organizations often find that an individual who is not involved with its regular work can help with the planning process. An outside consultant can facilitate the process so leadership can make decisions about mission, vision, goals, and implementation (Mittenthal, 2002).

Toward Cooperation and Collaboration with the Michigan SIDS/SUID Program

The Himmelman model describes cooperation as requiring greater organizational commitments from the partners which may include written agreements. Such was the case in Michigan. After several years of working together to implement the Michigan SIDS Task Force and Back to Sleep campaign, Tomorrow's Child and the state SIDS program had established a higher level of trust and shared responsibility. The private/public partnership was formalized when the state health department awarded the contract for the SIDS program to Tomorrow's Child. By moving the contract, a systems change had been implemented that would assure community involvement and continued advocacy to sustain the SIDS program. Tomorrow's Child soon called itself Tomorrow's Child/Michigan SIDS to reflect this integration.

The formal agreement between Tomorrow's Child and the state health department caused the partnership to quickly advance from the cooperation stage to collaboration. The health department designated a part-time SIDS nurse consultant to provide technical assistance and oversight. Risk, responsibilities and rewards were shared. Private and public resources were combined to support the SIDS program. The MCH director served on the Tomorrow's Child Board of Directors and the Executive Director began to participate in the state infant mortality initiatives.

Systems Integration to Address SIDS/SUID

Systems integration is designed to change service delivery for a defined population and involves fundamental changes in the way agencies share information, resources, and clients (Dennis, et.al. 1999). In particular, systems integration focuses on reducing barriers, coordinating and improving existing services and developing new programs to improve the availability, quality, and comprehensiveness of services (Miller, 1996).

System integration requires the creation of formal relationships among agencies within and across systems. (Agranoff, 1991; Cocozza et al., 2000). Awarding the state SIDS contract to Tomorrow's Child was the first step. Over the past decade, the lines between Tomorrow's Child and the Michigan SIDS/SUID program have blurred and the partnership steadily progressed towards system integration. Integrating the nonprofit organization and SIDS/SUID program allowed it to function

more fluidly, to scan the environment broadly and respond more rapidly to concerns, and to identify resources and link them together. (The Lewin Group, 2003).

Michigan was then poised to develop an integrated system with an increasing number of members. This system enabled Michigan to take on the new challenges presented by state data which indicated that an approach and a method broader than back to sleep was needed to impact SUID.

Response to Changing Epidemiology Requires Organizational Transformation

State vital statistics indicated that, although the SIDS rate was declining, the overall postneonatal rate had stagnated. The understanding of SIDS and the historical concept of 'not preventable' was beginning to change. Many of these sudden infant deaths were not SIDS, and involved modifiable risk factors, including sleep related factors, meaning that they may have been preventable.

One of the major challenges confronting SIDS programs was that, although there was an apparent decrease in SIDS rates, the number of referrals for grief services had not declined. In Michigan's situation, the referrals for other infant deaths were actually increasing. The causes varied and included accidental, suffocation, asphyxia, undetermined, sudden unexpected death in infancy, and sudden unexpected infant death. A significant number of referrals were for premature and low birth weight babies. In 2003, of the 341 postneonatal infant deaths in Michigan, only forty six were classified as Sudden Infant Death Syndrome (Grigorescu, 2004b).

For many programs, the expansion from SIDS to SUID and other infant deaths has been difficult, yet the transition from providing direct services related to only to SIDS deaths to providing systems leadership for SUID is a

critical step. Tomorrow's Child/Michigan SIDS used group process techniques to navigate a new direction. The organization was contemplating what felt like a seismic shift and, given the intensity of the issues, recognized that a different type of expertise would be required. For any organization, this phase offers both great risk and opportunity, and requires deliberate and professionally guided processes.

The state public health department was quick to change the mission of the SIDS program. Conversely, the parent nonprofit partner, Tomorrow's Child, struggled with expansion into other infant deaths. Tomorrow's Child's approach to the conflict may be instructive for organizations evaluating their role and relevance in this complex new SUID environment. It hired a strategic planning professional to facilitate an extensive eighteen month process with the Board of Directors. The planning sessions were data-driven: the state MCH epidemiologist presented infant mortality rates, disparities, demographics, trends in SIDS and postneonatal deaths, and the possible diagnostic shift. Internal and external stakeholders were surveyed to assess their perception of Tomorrow's Child and their response to a possible change in mission. The Board reviewed the organization's history, variation in services, and changes in funding streams.

At the conclusion, the facilitator recommended that the mission statement be revised to accurately reflect the services being provided (Monahan Associates, Inc., 2001). This process also brought the issue of racial disparities into focus and shifted the mission to address them. After thorough consideration of the issues, the Board resolved to be inclusive in its governance, structure and services:

> *"We must move forward to address the disparity issue, continue to include people of color on our Board, and recruit persons who have been affected by the death of an infant from a cause*

other than SIDS. The organization is addressing an unserved and underserved population with its risk reduction and grief programs. The mission and organization name should be changed to reflect the services being provided."

The revised mission created significant potential to expand services, programs, capacity building and funding. The strategic plan provided an infrastructure that would sustain Tomorrow's Child/Michigan SIDS and move the private/public relationship closer to full integration.

Developing a Systems-Change Approach for Infant Safe Sleep

State level data led the expanding coalition of systems partners to the conclusion that Michigan needed an approach that went beyond the Back to Sleep initiative to save infant lives. Although the state had been blanketed with Back to Sleep information, professionals and communities were reporting that the Back to Sleep message was inconsistent and often inaccurate. Despite its extraordinary successes, Back to Sleep had not been institutionalized. In addition, new data within Michigan suggested that additional behavioral changes related to infant sleep might be crucial to addressing the broader array of SUID that was occurring. A new initiative, Infant Safe Sleep was conceptualized to address the full range of issues that the state data were reflecting.

The success of the data driven, facilitated process for transforming Tomorrow's Child/Michigan SIDS suggested that a similar data-driven strategic planning process should be implemented for the Infant Safe Sleep initiative. Back to Sleep was a public health education campaign and was launched with such urgency that procedures had not been implemented to measure outcomes. Acceptance of infant sleep messages requires changing the values, knowledge, practice and beliefs of providers and caregivers. With the newly proposed Infant Safe Sleep initiative, Tomorrow's Child/Michigan SIDS proposed a systems-change approach with interventions that could be permanent and sustainable. Unlike Back to Sleep, effort was made to assure that Infant Safe Sleep initiatives would include evaluation and measurable outcomes. Evidence obtained from evaluation could help ascertain if the initiative was a success and feedback could guide any changes or adjustments that needed to be made.

Back to Sleep had national support but Infant Safe Sleep as Michigan began the process, still lacked federal or state endorsement. Instead, the campaign was launched on the basis of the relationships that had been built among the partners in the growing, integrated system, their common understanding of the issue, and shared commitment to reducing infant mortality. Michigan's Infant Safe Sleep campaign began as a true partnership.

As with Back to Sleep, the benefit of having the nonprofit organization, Tomorrow's Child/Michigan SIDS, initiate the early stages of Infant Safe Sleep was that it was not confined by bureaucracy, changes in political administration or funding limitations. Strategies included tapping the developing integrated system to partner on state and local summits on infant safe sleep, engage print and broadcast media coverage, and secure additional funding for the campaign. The systems and infrastructure established with Back to Sleep provided the foundation for Infant Safe Sleep and expedited the work. Tomorrow's Child/Michigan SIDS sought community input to build support for the new materials, and convened public health and healthcare professionals to draft the teaching tools that would be required. Local Back to Sleep coalitions began converting to Infant Safe Sleep coalitions to assist with the campaign. Health professionals and local coalitions tested the draft materials with clients for cultural and

linguistic competence. Tomorrow's Child obtained grant funding to produce and distribute the first Infant Safe Sleep brochures.

Engaging the Integrated System

While starting the initiative within the private sector provided the flexibility and funding, continuing the effort needed the public sector's involvement. Tomorrow's Child/Michigan SIDS and the Infant Safe Sleep proponents recognized that the campaign needed the credibility and authority of state agency leadership. Once again, the strategy in Michigan was to gather key stakeholders. The Michigan Department of Community Health and Department of Human Services provided the leadership and convened the Michigan Infant Safe Sleep Workgroup to create a plan that would integrate a consistent Infant Safe Sleep message. Participants included state health and human service agencies, education, academics, mortality review teams, pediatricians, childcare, local communities, breastfeeding advocates, Tomorrow's Child/Michigan SIDS and others (Michigan Department of Community Health, 2004). See page 22 for a more detailed description of the consensus process. The Infant Safe Sleep Final Report completed by the Workgroup called for systems-change among health providers, childcare, state government, health associations and others. The final recommendations also called for an interagency committee to oversee implementation and assure accountability—a new part of the integrated systems governance infrastructure (Michigan Department of Community Health, 2004)

Expanding the Sphere of Influence

Reaching consensus on the Infant Safe Sleep Final Report was a remarkable accomplishment. The recommendations provided a plan of action that would integrate a consistent safe sleep message in state agencies, healthcare providers and non-traditional

partners. However, expanding the Infant Safe Sleep campaign to the private sector required the authority of state government. Formal support by state leadership would both legitimize and sustain the recommendations. Circling back to the Directors of the Department Community Health and Department of Human Services who had originally convened the Infant Safe Sleep Workgroup, Tomorrow's Child/Michigan SIDS requested an opportunity to present the Final Report to the Governor's Children's Cabinet. The MCH director and Tomorrow's Child/Michigan SIDS presented together and the Cabinet endorsed the Final Report, giving Michigan the distinction of the being the first state with Infant Safe Sleep policies.

The Michigan Department of Community Health, Department of Human Services, and Department of Education are creating new ways to integrate Infant Safe Sleep into existing systems. The Department of Community Health is developing online professional training modules for its newly revised Maternal Infant Health Program (previously Maternal Support Systems/Infant Support System). The Department of Human Services is designing a Safe Sleep logo and Web site providing linkage between the public and private sector partners. Distribution to personnel of the state Infant Safe Sleep information and training continues throughout the state. The Governor's Great Start initiative is promoting Infant Safe Sleep to families throughout Michigan.

Tomorrow's Child/Michigan SIDS has continued to bridge with the private sector to promote systems change. The public sector is responding by sharing responsibility and committing resources to Infant Safe Sleep. In March 2007, the Michigan Health and Hospital Association convened Michigan's 20 largest delivery hospitals to secure participation in hospital safe sleep projects. The Michigan Association of Health Plans and Tomorrow's

Child are finalizing a pilot project to create standard education protocols, materials, and evaluation tools for clinics and physician practices affiliated with Medicaid health plans. Those protocols, materials, and evaluation tools will be extended to the remaining Medicaid plans through the professional association. Other health and human service professional associations are highlighting Infant Safe Sleep in conferences, workshops, and publications.

The System Works to Change Practice—Engaging Birthing Hospitals for Systems-Change

The broad, integrated system that has developed in Michigan has supported a number of concrete efforts to make enduring, systems changes. A systems-change approach to Infant Safe Sleep is significantly different from the direct service model of the traditional SIDS program. Tomorrow's Child/Michigan SIDS chose birthing hospitals as the first site to pilot a systems-change intervention. The decision was based on data and experience which demonstrated that hospitals had a profound influence on, and modeled behavior for, the new parent. However, anecdotal evidence suggested that health professionals still did not believe or teach Back to Sleep. Findings from the Pregnancy and Risk Assessment Monitoring System and national studies indicated that the early Back to Sleep message appeared to have had a lesser impact on the infant sleep practices of African-American women. Vital statistics and the Perinatal Periods of Risk model indicated that the hospital projects should be implemented in communities with high disparity between Black and White infant mortality rates (Colson & Joslin, 2002; Bullock, Mickey, Green, & Heine, 2004; Michigan Department of Community Health, 2003; AAP, 2000; Caravan Opinion Research Corporation International, 2000; Hauck et al., 2002; & Flick, White, Vemulapalli, Stulac, & Kemp, 2001).

Using the data described above, Tomorrow's Child/Michigan SIDS sought and was awarded a three-year grant from The Skillman Foundation to institutionalize Infant Safe Sleep in two birthing hospitals in city of Detroit (Tomorrow's Child/Michigan SIDS, letter of intent to The Skillman Foundation, October 18, 2002). The projects included evaluation and developed standardized policies, professional training curricula and patient education. Tomorrow's Child/Michigan SIDS convened the internal workgroup, developed the plan, provided information and expertise, monitored progress, and ensured adequate resources—a role quite different from the direct service model of the traditional SIDS program. See page 21 for a fuller description of this activity.

Building Sustainable Resources for an Integrated System

As resources to support SUID specific endeavors as well as general public health activities has decreased, a constant challenge to state SIDS and Infant Death Programs is funding. As already noted, 82% of current SIDS and Infant Death Programs note insufficient funding to address the needs of their states. Based on the Michigan experience, systems building and the partnerships and joint ownership for SUID efforts can create opportunities for greatly increasing the pool of resources available to address risk reduction and bereavement support. The formal relationship between the nonprofit organization and state health department contributed to the sustainability of the Michigan SIDS/SUID program and enabled increased support by leveraging official resources. Facing continuing tight budgets and lack of resources, other SIDS/SUID programs may want to consider opportunities to integrate resources and expertise with community and private sector resources. (The Lewin Group, 2001)

Strategic Use of Private and Public Partners

Involving Tomorrow's Child/Michigan SIDS was an effective approach to filling gaps left by budget and human resource shortfalls in the SIDS/SUID program. By partnering with a nonprofit organization, the Michigan SIDS/SUID program was able to enhance resources needed to maintain the public health activities. Services were expanded without significantly increasing the commitment of state resources. Because of independence from government, Tomorrow's Child/Michigan SIDS could seek funding from public and private sources without necessarily being bound by government agency priorities. (The Lewin Group, 2003)

Developing A Sustainable Approach to Funding

As with most nonprofit human service organizations, the early fundraising efforts in Michigan began with local events involving family and friends of bereaved parents. Special events typically did not involve corporate sponsorship or engagement. Events generally had a life cycle of 3-5 years, depending on the energy and interest of the founding parents.

As with programs, the goal with fundraising is sustainability and integration. Resources must be predictable and consistent in order to create budgets, maintain an infrastructure and assure continued services. Three factors can move fundraising beyond grassroots and enhance fundraising efforts. One is strong programs. Programs that are meeting important community needs and demonstrating results will sell themselves. The second is a board that is committed to its fundraising responsibilities and takes their role in fundraising seriously. The third is professional development staff.

Current day fundraising has become systematic and almost scientific in its approach. And all fundraising begins with the mission.

Tomorrow's Child/Michigan SIDS has found that its mission—infant health and well being—is extraordinarily compelling. The issue has strong private sector allies that have the capacity and the motivation to contribute financial resources to the cause. New sources of funding have included foundations, corporations, and other health and human service organizations.

Grants have been a significant source of funding for Tomorrow's Child/Michigan SIDS. Funders want evidence to support the application and they want evaluation to assure the expected outcomes. Increasingly, foundations are becoming more interested in how their grant will be leveraged to expand and sustain the programs being funded. Grantors for Tomorrow's Child/Michigan SIDS have included private, community, family and corporate foundations. Relationships with grantors are nurtured and respected and, when possible, multi-year grants have been sought. The application process started with aligning the mission with the grantor's core interests. While no means exhaustive, areas of interest have included:

- parenting;
- high risk families and children;
- infant health and well being;
- systems change;
- community collaboratives and coalition building;
- child care;
- minority health; and
- family preservation.

Tomorrow's Child/Michigan SIDS has been able to use foundation resources to leverage new sources. For example, funding from The Skillman Foundation (see page 24) for the hospital-based pilot projects was used to leverage matching funds from Michigan's

Health Disparities Reduction Program targeting communities with highest disparity in infant mortality. Findings from these pilot projects influenced the interventions initiated with the $250,000 allocation for Infant Safe Sleep from the state health department (page 22). A portion of the $250,000 funds was matched by the health plan association.

Basic Fundraising Concepts

The Starting Point
Fundraising begins with mission. Every organization has a responsibility to understand its rationale for existence. Mission is the means for bringing individuals, corporations, foundations, and others together to carry out mutual interests.

Strategic Decision Making
Fundraising supports the goals and programs articulated in the strategic plan. Ideally, the organization develops a fundraising plan that reflects what is known about organizational function.

Making the Case
For effective fundraising, the organization must make 'the case' giving all the reasons why anyone should contribute. The case articulates the problem, goals, services, quality effectiveness, and should validate the need for philanthropy.

Building an Information Base
Research can help assure that fundraising efforts will be effective by matching the potential contributor's interests and needs with the organization's mission, goals, and objectives. Sources of contributions include corporations, foundations, bequests and individuals.

Annual Fund
Annual fund means the organized effort to obtain gifts on a yearly basis to support general operations. Strategies include special events, grant proposals, direct mail, phone appeals, personal solicitation, recognition groups, and challenge gifts. Selection of the appropriate strategy is based on the ability of each to produce maximum gifts and support, and the resources, budget and staff available to carry out the program (The Fundraising School, 2002).

In seeking resources for SIDS/SUIDS programs, all possible sources should be considered. The private sector has been a valuable partner with Infant Safe Sleep and forming partnerships between state and the private sector has been an effective way for Tomorrow's Child/Michigan SIDS to leverage additional program funds. Corporations, businesses, foundations and healthcare associations have supported the mission by hosting and sponsoring special events. Likewise, these entities have expanded the circle and have linked with their contractors, suppliers, constituents and allied associates to request additional sponsorship and involvement in events.

Fundraising can be an all-consuming activity, requiring a balance between program management and raising funds. Hiring a fund development professional or seeking outside expertise is a must for most organizations. As with programs, an infrastructure should be built and standards set for ethical activities. Ideally, fundraising initiatives and programs should be integrated. Fundraising is generally not a favored task for SIDS/SUID programs but is quickly becoming a necessity. For those that may be uncomfortable with this new dynamic, keep in mind that the goal is to advance the mission: saving babies' lives.

Assuring Cultural and Linguistic Competence

The NCCC definition of cultural competence holds that cultural competence requires that organizations: have a congruent defined set of values and principles, and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally. (See page 19 for a full definition of cultural competence.) The NCCC definition of linguistic competence stipulates that it is the capacity of an organization and its personnel to

communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. (See page 21 for a full definition of linguistic competence.)

The Michigan experience demonstrates several aspects of how cultural and linguistic competence was incorporated during the process of moving from parallel efforts to an integrated system. The work of building systems involves cross-cultural work at several levels. First, there is the need to address the racial,

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Cultural and Linguistic Competence in Developing a Community-based, Statewide System to Address SIDS and Infant Safe Sleep

The systems governance infrastructure and activities reflect the following:

- Mission statement that articulates cultural and linguistic competence

- Membership on boards and advisory groups that reflect the diversity of communities served and interested stakeholders

- Staff and volunteer recruiting and retention that reflect diversity of the communities served

- Ongoing review of demographic trends in the communities affected by SUID

- Formal process to identify and acquire knowledge about health and mental health beliefs and practices of populations served

- Activities and approaches that respects and reflect cultural beliefs, values, and practices of the intended audiences

- Formal process that assures meaningful involvement of community members and key stakeholders in determining need for any action and in designing, implementing and evaluating the approach

- Policy and dedicated resources to assure linguistically competent approaches

- Capacity to address the dynamics of difference within the organization

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ethnic, linguistic and cultural diversity within the state in providing risk reduction and bereavement support services to families. As data on racial disparities in SUID in Michigan grew, the urgency of creating culturally and linguistically competent approaches increased. There is, however, a second level at which cross-cultural work was critical to the systems-building process. Collaboration and systems building entail bringing together multiple individuals, professional groups, constituencies and institutions with a stake in addressing infant well-being, each of which brings a culture—a set of beliefs, values, ways of interacting, and world views. Working to integrate all of those perspectives into a common purpose with a set of common goals and shared actions required the approaches and perspectives of cultural and linguistic competence.

Addressing Cultural and Linguistic Competence at the Family and Community Levels

Cultural and linguistic competence in effectively implementing risk reduction efforts and in providing appropriate bereavement support evolved over the course of the systems integration journey in Michigan. Cultural competence was needed to understand and thus effectively and respectfully address: 1) beliefs about the causes of SUID, 2) long-held approaches to child rearing, 3) ways of seeking support, 4) credible sources of information, and 5) assurance that the families and communities served were full partners in planning, implementing and evaluating the approaches chosen. Linguistic competence was key to assuring that the information provided was understandable and usable by all families and communities—this involved not only those with limited English proficiency, but also those with low or no literacy skills, those with low health literacy and individuals who required information in accessible formats.

Family Involvement in Program Planning

The early parent and family organizations in Michigan were created and run by families that did not necessarily reflect the full racial, ethnic, linguistic or socioeconomic diversity of the state. There, was, however, an opportunity for the families that were involved to begin to shape the kinds of services and supports that met their specific needs. On the public side, the initial Michigan SIDS program was a traditional public health program in the sense that professionals defined the policies, services, and interventions, and consumers were minimally involved. In 1991, however, when the regional SIDS parent groups merged to form Tomorrow's Child, the parent community advocated for and succeeded in attaining consumer input in the public SIDS program on planning and implementation of bereavement services for families. This was a first step in utilizing culturally competent approaches to SIDS in Michigan.

Expanding Board Membership to Address Cultural and Linguistic Competence

In the following years, Tomorrow's Child recognized that its programs needed to seek input of a far broader audience to address cultural and linguistic competence. Tomorrow's Child utilized the findings of the Michigan SIDS Task Force to study these issues. Because of the Task Force recommendations, the Board of Directors of Tomorrow's Child understood the need for members with more policy and healthcare expertise. The Task Force Report had also increased the Board's awareness of the need for diversity among its members. Through strategic planning and purposeful design, the Board of Directors sought representation in two areas: 1) healthcare policy and 2) diversity. The MCH Director was immediately recruited to join the Tomorrow's Child Board of Directors. She assisted in identifying and recruiting potential candidates. With their input, the Board was strengthened by the inclusion of culturally diverse members with expertise in policy, healthcare and medicine.

National Center for Cultural Competence Definition of Cultural Competence

Cultural competence requires that organizations:

- have a congruent defined set of values and principles, and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally.

- have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge, and (5) adapt to diversity and the cultural contexts of communities they serve.

- incorporate the above in all aspects of policy development, administration, practice and service delivery, and systematically involve consumers, families and communities.

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.

(Modified from Cross et al., 1989)

Dedicated Resources Support Cultural and Linguistic Competence

Although the overall SIDS rates in Michigan had declined 43% following implementation of the Back to Sleep Initative, significant racial disparity continued. Michigan's experience was consistent with national findings. The national directive for the Back to Sleep initiative in 1997 to develop culturally appropriate interventions opened the door for full partnership between the state SIDS program and Tomorrow's Child. A new MCH Director had been appointed and he awarded the contract to Tomorrow's Child, formalizing the partnership. Acknowledging the disparity in SIDS rates, the new MCH director successfully advocated the legislature for a one-time appropriation of $350,000 for a culturally competent public awareness campaign and community-based Back to Sleep intervention. Tomorrow's Child offered to match the funds through grants and fundraising initiatives. By integrating public and private resources,

services were expanded and public health capacity was increased to specifically address families at high risk in the African-American community. The state health department and Tomorrow's Child combined funds to hire new SIDS program personnel: the state contract was used to hire a full-time public health nurse, a portion of the one-time appropriation supported a community-based nurse, and Tomorrow's Child obtained a grant for a risk reduction coordinator. The new staff was culturally diverse and possessed the knowledge and relationships needed for community engagement.

Meaningful Community Engagement to Address Cultural and Linguistic Competence

The partners wanted to assure meaningful community participation in planning the state's culturally competent Back to Sleep campaign. Pursuant to the state contract, Tomorrow's Child/Michigan SIDS was expected to provide technical assistance to Michigan communities seeking to implement a Back to Sleep initiative. Detroit, which had one of the highest disparity rates in the state, was a priority. Tomorrow's Child/Michigan SIDS, backed by the authority of the state health department, asked the Detroit Health Department to partner in a culturally relevant Back to Sleep campaign.

Together, Tomorrow's Child/Michigan SIDS and the Detroit Health Department convened a Back to Sleep coalition which was composed of community members, local public health, alternative education, infant mortality projects, teen mother programs, community hospitals, representatives from the Native American tribes in the city, the Arab community, and others. The Detroit Back to Sleep coalition designed and helped implement the new culturally competent Back to Sleep campaign. Activities included:

- conducting an informal pre-campaign survey;

- reviewing all materials and providing input on content and cultural competence;

- contributing to and recommending approaches to integration of message into community;

- discussing and recommending allocation of campaign materials, and committee and Tomorrow's Child resources;

- collecting data on Detroit infant deaths by zipcode;

- disseminating campaign materials to neighborhoods with highest incidence of infant deaths;

- administering an informal post-campaign survey to target population; and

- sustaining committee activities and Back to Sleep intervention.

To address the African-American SIDS disparities, focus groups and interviews helped determine the communication tools and the message content. Participants were African-American women of child-bearing age and senior caregivers such as grandmothers and aunts. Community feedback was instrumental in assuring that the materials were created in a linguistically competent way.

Addressing Linguistic Competence in Materials Development

Back to Sleep Materials were developed in Spanish and the new Infant Safe Sleep materials are available in Spanish and Arabic. However, the efforts of Tomorrow's Child reflected the understanding that linguistic competence extends beyond the issues of English proficiency. The initial Back to Sleep written materials created for Michigan were at the 8th grade reading level. Materials from the national Back to Sleep Campaign were determined to be at an even higher reading level. Community input indicated that these materials would not be useful to many families with limited literacy. Tomorrow's Child then consulted the state Medicaid requirements for written materials for consumers. It was determined that information

needed to be presented at a maximum of a fifth-grade reading level and with many pictures and illustrations. This approach was embraced by the community.

Tracking Racial and Ethnic Specific Data Guides Continued Efforts

Following the Back to Sleep efforts, Michigan continued to follow health data related to disparities. African-American infants in Michigan were almost three times more likely to die than White infants. The early Back to Sleep message appeared to have had less of an impact on the infant sleep practices of African-American women (Michigan Department of Community Health, 2003). Black women were least likely to place infants on their backs than any other race or ethnicity and had the highest rate of bedsharing. Bedsharing deaths were twice as common in Black infants as were deaths on nonstandard sleep surfaces such as mattresses or sofas. African-American mothers also had increased use of pillows, soft bedding and stuffed toys (AAP, 2000; Caravan Opinion Research Corporation International, 2000; Hauck et al., 2002; & Flick, White, Vemulapalli, Stulac, & Kemp, 2001). This data was utilized to craft ongoing systems change efforts.

Community Engagement Guides Infant Safe Sleep

Community engagement to address cultural and linguistic competence became institutionalized in Michigan's response to SUID. When Michigan expanded from Back to Sleep to its Infant Safe Sleep initiative, engaging the community was the way to do business. Turning to the systems infrastructure and relationships established with Back to Sleep, Tomorrow's Child sought community input to build support for the new materials, and convened public health and healthcare professionals to draft the teaching tools that would be required. Local Back to Sleep coalitions began converting to Infant Safe Sleep

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National Center for Cultural Competence Definition of Linguistic Competence

The capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. Linguistic competency requires organizational and provider capacity to respond effectively to the health literacy needs of populations served. The organization must have policy, structures, practices, procedures, and dedicated resources to support this capacity. This may include, but is not limited to, the use of:

- bilingual/bicultural or multilingual/multicultural staff;
- cross-cultural communication approaches
- cultural brokers;
- foreign language interpretation services including distance technologies;
- sign language interpretation services;
- multilingual telecommunication systems;
- videoconferencing and telehealth technologies;
- TTY and other assistive technology devices;
- computer assisted real time translation (CART) or viable real time transcriptions (VRT);
- print materials in easy to read, low literacy, picture and symbol formats;
- materials in alternative formats (e.g., audiotape, Braille, enlarged print);
- varied approaches to share information with individuals who experience cognitive disabilities;
- materials developed and tested for specific cultural, ethnic and linguistic groups;
- translation services including those of:
  - legally binding documents (e.g., consent forms, confidentiality and patient rights statements, release of information, applications)
  - signage
  - health education materials
  - public awareness materials and campaigns; and
- ethnic media in languages other than English (e.g., television, radio, Internet, newspapers, periodicals).

Goode and Jones (2006)

coalitions to assist with the campaign. Health professionals and local coalitions developed the draft materials with clients for cultural and linguistic competence. Tomorrow's Child obtained grant funding to produce the first Infant Safe Sleep materials and distribution began in March 2002. Continuing efforts to evaluate the effectiveness of the Infant Safe Sleep initiative utilize community engagement. The campaign is changing based on community feedback and evaluation findings. Next steps need to include assessment of knowledge and adherence at the community level. Focus groups of African-American mothers have been completed and will provide insight into knowledge, practice and beliefs about infant sleep environment. Questions include the role of family and community in learning about infant care practices. Existing strategies will be modified and new ones will likely emerge.

Organizational Structure and Policy to Support Cultural and Linguistic Competence

Organizational structure and policy also evolved to support cultural and linguistic competence. As already noted, when Tomorrow's Child/Michigan SIDS determined that there was a need to transform the organization from one that exclusively addressed SIDS to one that would provide leadership in creating an integrated system to address SUID, it hired a strategic planning professional who facilitated an eighteen month process with the Board of Directors. That process also led to a change in the mission and strategic plan of the organization to address cultural and linguistic competence. See page 12 for the changes to the mission statement.

Working Across the Cultures of Agencies, Professions and Stakeholders

The final array of individuals, organizations and interests that are reflected in the Michigan integrated system to address SUID is very diverse in terms of values, beliefs, areas of focus and approaches. An important aspect of culturally competent organizations is the capacity to deal with the dynamics of difference. Whenever individuals from different cultural backgrounds and perspectives (including professional or institutional cultures) are brought together, there is likely to be some conflict and potential for cross-cultural misunderstanding. The capacity—skills and processes—to deal with these potential conflicts is central for a culturally competent organization In Michigan, Tomorrow's Child/Michigan SIDS, as a key leader and convener for the broad, state-wide integrated system demonstrated a number of culturally competent approaches.

Addressing the Dynamics of Cultural Differences

As Michigan approached developing the new, Infant Safe Sleep initiative, it was clear that a very broad set of stakeholders had to be engaged, their perspectives understood, their concerns addressed and collective actions created that worked within the organizational and group cultures they represented. Acceptance of the infant sleep messages requires changing the values, knowledge, practice and beliefs of providers and caregivers.

Infant Safe Sleep had a far broader set of systems partners than Back to Sleep had garnered. The Michigan Department of Human Services, Department of Education, social services, child welfare, law enforcement, child care, parent education and local communities were now at the table. In addition, as already noted, nutrition and breastfeeding programs were concerned that safe sleep might have a negative impact on the mother's decision to nurse her baby. The topic was controversial and emotional with strong advocates on all sides. The MCH Director created an Infant Safe Sleep Workgroup which was officially convened by the Michigan Department of Community Health and Department of Human Services.

Participants included state health and human service agencies, education, academics, mortality review teams, pediatricians, childcare, local communities, breastfeeding advocates, Tomorrow's Child and others.

Recognizing the diversity of cultures that were being brought to the table, a plan was developed to deal with the dynamics of difference as part of the cultural competence of the organization. In order to improve the group dynamics and process, two sub-committees were formed: the Data Committee and Message Committee. Early in the process, agreement was reached on guiding principles, among group members:

1) The mutual goal was to save babies' lives.

2) The messages and interventions must be consistent with the AAP recommendations.

3) Discussions and recommendations would be evidence-based.

4) Committee interaction would be non-judgmental.

5) The interventions would strive to create permanent, systems change.

A few members of the Message Committee had opposing and strongly held beliefs about infant sleep practices. A number of group process strategies helped manage the conflict and emotionality of the discussion. Most beneficial for the discussions:

1) The Committee was given a short timeframe of six months to meet and finalize recommendations.

2) The meetings were held in a friendly, low-key, non-institutional setting that created a sense of 'togetherness' about the work.

3) Relationships were valued and key members worked to build trust in and outside of the Committee discussions.

4) The core message was a positive statement, not a mandate. The rationale was:
   – Those with opposing beliefs might entrench or leave the committee;
   – A mandate of any sort would estrange families and providers;
   – Everyone could agree that the goal was to save infant lives.

5) A draft core message was presented by the state health department and then delegated to the Message Committee for discussion. The rationale included:
   – Leadership had a birds-eye view of the issue and would be more objective.
   – The heat of the debate might be reduced if the draft was presented by leadership.
   – The leadership's authority could be invoked in order to move the discussion, if necessary.

The core message presented by state health leadership was: *Every Baby Is Placed to Sleep in a Safe Environment* (Michigan Department of Community Health, 2004a). With the AAP recommendations in hand, the Message Committee was able to identify fourteen different risk factors. The success was immediate—they agreed on thirteen of the fourteen factors. Three audiences were identified: childcare providers, professionals and general public. By choosing to start with childcare providers, the Committee agreed on fourteen of the fourteen risk factors, including a strong statement that infants in child care should not sleep in an adult bed. With each successive meeting, the Committee members gained more confidence in each other and in their ability to problem-solve. Breastfeeding was discussed and the Committee unanimously and unequivocally agreed to recommend and support breastfeeding.

With this carefully planned and executed approach to managing the dynamics of difference, Michigan was able to keep the

diverse key stakeholders in the process and develop approaches that respected the diverse personal, professional and organizational cultural perspectives of the group. As a result, the complex set of partners needed to create a state-wide integrated system to address SUID was able to move forward.

Impacting Professional and Institutional Culture in Systems Change

As already noted the experience with Back to Sleep demonstrated that hospitals had a profound influence on, and modeled behavior for, the new parent. An approach was needed that understood and respected the cultures of the labor and delivery nurses and the hospitals that employed them. Engaging those communities was key to understanding the professional and institutional cultures that had created the resistance to promoting risk reduction messages. In order to create culturally competent approaches to this issue, Michigan worked with nurses and others within the institutions to understand what would influence nursing beliefs and practices. Public health messages designed for families and engagement approaches for families would not work with these cultures. Approaches have included training developed by and for nurses in the hospitals and understanding that in hospital cultures, policy is key to changing behaviors.

Conclusion

This report has presented a rationale for a shift in roles for state SIDS and Infant Death programs from service delivery to leading systems integration efforts. It has provided the story of one state—Michigan—in its journey to leading and supporting an integrated systems change approach to address SUID. Examples of how programs can transform to meet the current complex challenges in addressing risk reduction

and bereavement support within a state are provided as well as examples of how to achieve these changes in an environment of shrinking public health resources. While each state has a different set of potential systems partners and a different history, the lessons that Michigan has learned can be useful to other states including:

- strategic use of the specific roles and strengths of public and private partners;

- use of professionals with skills in strategic planning and fundraising/development to augment the skills of service providers and public health professionals;

- use of culturally and linguistically competent approaches to engage the multiple stakeholders needed to create a statewide, integrated systems change process with their individual, community, professional and/or institutional cultures;

- use of data to drive collaboration and systems building;

- focus on systems change as the key to supporting behavior change of individuals and families; and

- use of evaluation and quality feedback to improve initiatives, point to next steps and provide data to use with potential funders.

Supporting State Programs for a Paradigm Shift

As is illustrated in the Michigan journey to an integrated systems approach, making this paradigm shift is not easy. If states are to pursue it, they will need considerable support. First, and foremost, it is essential that federal, regional and state MCH programs support and promote the paradigm shift. Promoting the shift entails embracing the philosophy of integrated systems to address SUID as well as demonstrating the will to do so in policies, funding decisions and guidance. Second, resources to support states in making the shift will be needed—fiscal, personnel and

knowledge resources. Thus, supporting a paradigm shift will entail identifying new resources and realigning existing resources within the systems context. Finally, there will be a need for technical support. Those needs will differ among the states, but may include:

- access to expertise and mentoring on systems integration;

- access to information and knowledge about systems building;

- opportunities and fiscal support for training and technical assistance to states who pursue systems integration efforts for SUID;

- opportunities to share knowledge and lessons learned among state entities addressing SUID; and

- support from national and federal programs that are implemented within states and communities in systems building related to SUID.

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Suggested Citation

Frank, S. and Bronheim, S. Spring 2007. *Building Integrated Systems to Address Sudden Unexpected Infant Death*. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

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The NCCC provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental health care delivery, administration, education, and advocacy.

The NCCC uses four major approaches to fulfill its mission including (1) Web-based technical assistance, (2) knowledge development and dissemination, (3) supporting a *"community of learners,"* and (4) collaboration and partnerships with diverse constituency groups. These approaches entail the provision of training, technical assistance, and consultation and are intended to facilitate networking, linkages, and information exchange. The NCCC has particular expertise in developing instruments and conducting organizational self-assessment processes to advance cultural and linguistic competency.

The NCCC is a component of the Georgetown University Center for Child and Human Development (GUCCHD) and is housed within the Department of Pediatrics of the Georgetown University Medical Center. The NCCC is funded and operates under the auspices of Cooperative Agreement #U40-MC-00145 and is supported in part by the Maternal and Child Health program (Title V, Social Security Act), Health Resources and Services Administration, U.S. Department of Health and Human Services (DHHS).

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