



National
Center
for
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Competence

Policy Brief

GEORGETOWN UNIVERSITY CENTER FOR CHILD AND HUMAN DEVELOPMENT ■ UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

Infusing Cultural and Linguistic Competence into the Multiple Systems Encountered by Families Following the Sudden, Unexpected Death of an Infant

Introduction

In all cultures, birth and death are imbued with great significance, and a series of beliefs, customs and values attend each. When birth and death occur very close in time, the vital role that culture plays in supporting individuals and families and in imbuing this tragic experience with meaning must be respected and enhanced to support those who experienced the loss.

When an infant dies suddenly and unexpectedly, families and caregivers are thrust into a swirl of new people and multiple agencies and service providers at the time of overwhelming grief and unbearable sadness. Some of these encounters are designed to provide medical help and emotional support. Others are a function of legal requirements and the need to investigate the cause of death. Due to the number of systems and people who suddenly enter the lives of newly grieving families and caregivers, even supportive interventions may feel overwhelming and intrusive to those who have sustained the loss.

This Policy Brief provides a rationale for incorporating cultural and linguistic competence in the many programs, agencies and systems that families and caregivers encounter following the sudden, unexpected death of an infant. While Sudden Infant Death Syndrome (SIDS) is the focus of this document, the issues apply to any cause of sudden, unexpected death of a child. While the primary discussion relates to the impact of these systems on families, the broader term caregivers is also used. It is reported that 45% of children one year old and younger are in some type of child care setting. Approximately 93% of the 2.4 million individuals providing unpaid child care during a given week are relatives of the child (Center for the Child Care Workforce and Human Services Policy, 2002). A retrospective study of SIDS deaths from January 1995 through June 1997 showed that approximately 20% of SIDS deaths occurred in child care settings (Moon, Patel and Shaefer, 2000). Thus, when an infant dies, an extended network of caregivers is affected. This brief provides guidance on policies that support the infusion of cultural and linguistic competence into the complex array of providers, organizations, community coalitions, faith-based organizations, businesses and officials that become involved following such a death.

Rationale for Cultural Competence in Systems Families and Caregivers Encounter Following the Sudden and Unexpected Death of an Infant

■ Growing Diversity

The United States as a whole and many individual communities are experiencing rapidly shifting demographic patterns that challenge service delivery systems and public agencies to provide culturally and linguistically competent services. Based on data from the 2000 Census, approximately one-third of the U.S. population is from racially, ethnically and culturally diverse groups. From 1990 to 2000, the number of immigrants in this country increased by approximately 50% from 19.8 million to 30 million (U.S. Immigration and Naturalization Service, 2002a and 2002b). Not surprisingly, this influx of diverse populations has led to a multiplicity of spoken languages and many residents who have limited English proficiency. More than 10.5 million U.S. residents report they speak little or no English. This is up from 6.5 million in 1990 (U.S. Census Bureau, 2002).

The workforce that provides both center-based and home-based child care in this country is also diverse and becoming more so (Center for the Child Care Workforce and Human Services Policy, 2002; Whitebook and Phillips, 1999). As previously noted, relatives comprise a large proportion of childcare providers and reflect the diversity of the families served.

■ Continuing Disparities in Infant Mortality

In addition to growing diversity in this country, those families and caregivers most likely to be affected by a sudden, unexpected infant death are from racially and ethnically diverse groups despite the fact that infant mortality rates among the total U.S. population have been dropping steadily in the past decade. For instance, low birth weight, which disproportionately affects African Americans, has been increasing and is a leading risk factor for infant mortality among African Americans (National Center for Health Statistics, 2001). While SIDS rates overall have dropped precipitously since the institution of the Back to Sleep Campaign in 1994, those public health gains have not been equally distributed. African Americans and Native Americans have SIDS rates two to three times higher than the national average. Some Puerto Rican families also have elevated rates of SIDS (Matthews, 2000).

These two factors—growing diversity and continuing disparities—drive the urgent need for cultural and linguistic competence in the systems that families and caregivers encounter following the sudden, unexpected death of an infant.

Patricia and Lisandro Restrepo, who came to live in California from Colombia, South America, describe their experiences after the loss of an infant at birth:

“As Latinos, one of the most important aspects of our culture is spirituality. We cannot perceive reality and conceive life decisions without it. For us, Latinos, life is whole, we are whole. Nevertheless, what the health care system in America does is to compartmentalize us.

“One of the things that struck us during our own experience was to know that there were no support groups in Spanish for parents who had just lost their babies. We had the option of participating in a support group in English, but of course we wanted to be able to speak in the language of our soul. We wanted to share this time with people with the same cultural perspective and values as ours.”

■ Impact on Families and Caregivers

Loss of an infant creates distress over time

The sudden and unexpected loss of an infant is a traumatic event that affects families for years after the death (Shapiro, 1994). Researchers have found an array of psychological symptoms in parents who lose an infant with some effects still observable five years and more after the death (Vance, et al., 1995; Thuen and Schlytter, 1996). Siblings of the infant who dies are also significantly affected. They must deal not only with the trauma of the death, but with their parents’ grief and its impact on parenting and family functioning (Shapiro, 1994). More than three-fourths of siblings show immediate emotional effects with half still exhibiting problems almost three years later (Powell, 1991).

Cultures define family in different ways. It is not only the nuclear family that is affected by an infant’s death. Grandparents, aunts, uncles, cousins and even those who are connected through friendship, community or tribal ties experience the loss (Whelan, 2000). When families encounter experiences that do not respect and honor their culture or if they are unable to understand the interactions due to language differences, then the trauma is intensified and the support and healing are not forthcoming (Shaefer, 1999).

Factors that may intensify the trauma

A couple from Mexico who was served by the New York City Satellite of the New York State SIDS Center, wanted to bury their baby back in their home country. The parents, however, were undocumented and could not travel home. Through the support services they received, they were able to do so. They chose to send their baby's body back to Mexico accompanied by their pastor. Their relatives performed the rituals for the burial and sent photographs. The parents felt assured that their relatives had taken care of their baby in the proper way and this culturally competent support comforted them in their grief.

■ ***Impact on families and caregivers who are immigrants***

Depending on the length of time they have lived in this country, families and caregivers who have immigrated here face a particular set of issues when they suddenly and unexpectedly lose an infant. They may have left key support systems behind—family rituals, places and objects related to death and grieving. Some immigrants may fear interactions with law enforcement during the death investigation and worry that their immigration status will be affected or that vital services for their family will be withdrawn. Consequently, the process and the multiple encounters with numerous systems may intensify the trauma for families with limited English proficiency.

■ ***Impact on refugee families***

A subset of immigrants have additional issues that intensify the impact of an infant's death. Refugees are those immigrants who are fleeing war, political or ethnic persecution or, in some cases severe economic crisis. Since 1975, 2.5 million refugees have entered the United States (The Center for Victims of Torture, 2001). Most have experienced multiple traumas and many have experienced physical assault as well as psychological torture. It is estimated that up to one-fourth have been tortured in their countries of origin (Brown, 2000). Sexual assault is also common—four out of five women seeking help in their new homeland and half of the men were subjected to sexual torture (The Center for Victims of Torture, 2001). When they arrive in the United States they experience the traumas of resettlement. These multiple traumatic experiences have been linked to a variety of psychiatric disorders (Holman, Silver & Waitzen, 2000). These include Post Traumatic Stress Disorder, which has been found to make individuals more reactive to new traumatic situations (U.S. Committee for Refugees, n.d.). Thus the sudden unexpected death of an infant, whose birth may have symbolized a new hope and a new life, can create a psychological load that is overwhelming.

■ ***Impact on families who have experienced multiple traumas***

The death of an infant is just one in a series of traumatic life events for some families and caregivers. Palmer (1999), for example, reported that in a sample of poor inner city African American women who had lost an infant, half reported that from one to five other family members died within the same year. Mortality associated with health disparities and rates of violence within many urban communities disproportionately impact racial and ethnic groups. Distrust of and experiences with discrimination by law enforcement, child welfare agencies, health care providers and other government bodies intensifies the trauma of the multiple systems that they encounter.

■ **Impact on Providers**

Dealing with the families' emotionality, feeling at a loss to comfort them and simply confronting the tragedy of an infant's death all take their toll on the many providers who work with families who lose an infant. Aside from the personal impact for these caregivers, there is a systemic impact—those with the most experience may burn out and leave the field. Exacerbating this workforce problem is the fact that too often these providers have little or no formal training to support them in working in cross-cultural situations.

An Emergency Medical Technician recalls being called to a home with an unresponsive infant:

“When we got there two women were screaming and crying. Neither spoke English. I didn’t even know who was the mother or if either one was the mother. We didn’t know how long the infant had been unresponsive, didn’t know if he had been sick. But worst of all, we had no way to comfort the women or explain to them what was happening. Since the baby died at home, in our town we had to wait for the police to arrive. It took them fifteen minutes—fifteen minutes of my feeling totally helpless.”

There are many types of providers in the system. Emergency Medical Technicians (EMTs), for example, are often among the first on the scene when an infant is found unresponsive. Responding to this type of emergency is one of many stressful events they encounter each day. Not surprisingly, EMTs have been reported to have high rates of stress, burnout and attrition (Vettor and Kosinski, 2000). While there are multiple sources of that stress, studies have reported that lack of a supportive working situation—from their team and supervisors—heightens work stress (Boudreaux & Mandry, 1996; Slaymaker, 2000). The lack of organizational policy and practices that support EMTs to communicate with families in the crisis situation, to be able to explain frightening emergency procedures, to get needed information to inform intervention or to understand a family’s reaction to trauma and grief due to cultural differences can be sources of such stress.

Those professionals who provide ongoing bereavement support also experience stress in dealing with this intensely emotional issue. A study of nurses providing bereavement support to families who had lost an infant reported distress that was manifest in many ways—sleeplessness, intrusion of thoughts about the families they served, fatigue, etc. One of the aspects of their work that they found very stressful was dealing with the families’ expressions of grief, often in intensely emotional ways (McClain and Mandell, 1994). Providing bereavement services to culturally and linguistically diverse individuals and families becomes more stressful in the absence of organizational policy, procedures and resources that support such efforts. Programs must have the organizational capacity to: 1) recruit and retain professionals who reflect the cultural and linguistic diversity of families served; 2) assure a workforce that has knowledge and skill sets to provide services in cross-cultural situations; 3) provide interpretation services; and 4) allocate resources and develop bereavement materials that are tailored to the cultural contexts of communities served.

The use of policies that build a culturally and linguistically competent systems and services not only provides support for the families and caregivers, it also enhances the competency and sense of effectiveness of providers. Culturally and linguistically competent policy and practice address provider stress and may decrease burn out and loss of talented workers in the field. Culturally and linguistically competent policies support and protect the caregivers.

■ Impact on the Community

Rates of infant mortality are considered a sensitive indicator of overall community health. Local approaches, which target specific problems and risk factors within a community have been shown to be highly effective in addressing racial and ethnic disparities in infant health (National Fetal-Infant Mortality Review Program, 2002). Communities need accurate and relevant data in order to develop the approaches needed to reduce risks and improve outcomes for infants. Data about rates and disparities may be a starting point, but communities need a broader process to understand the factors that lead to infant deaths in order to strengthen the community’s capacity to better support families and infants.

In many communities fetal and infant mortality reviews (FIMR) have been in existence for more than a decade. These community teams are comprised of representatives from the public health department, pediatric and obstetric providers, consumers, advocates, human services agencies, bereavement professionals, elected officials and others. They meet to review cases to learn how a wide array of local social, economic, public health, educational, environmental, safety and cultural issues relate to the tragedy of infant loss. The

number one area in which FIMR teams have made recommendations to communities has been around SIDS (Women’s and Children’s Health Policy Center, 2001a). A recent study of FIMR teams indicated that two key barriers encountered to effectively implement the model were difficulty locating parents for voluntary interviews and incomplete information from records (Women’s and Children’s Health Policy Center, 2001b). Families may be less likely to engage or may not provide complete and accurate information if they are frightened and distrustful of the process and alienated by lack of respect for their cultural values and needs. Gaining the information needed will be hampered when interviews and interactions are not in a language families, caregivers or others present at the death scene understand. Thus, cultural and linguistic competence in the systems that families and caregivers encounter after the sudden and unexpected death of an infant benefit the health of the community as a whole.

Cultural and Linguistic Competence in a Complex and Fragmented System

The multiple systems and supports encountered by families and caregivers following the sudden and unexpected death of an infant require the development of policies, procedures and practices across multiple agencies and organizations. This section provides a set of checklists for each of the many layers of the system to consider in pursuing cultural and linguistic competence.

- 1. First responders:** When the child is found unresponsive, emergency personnel are typically summoned. Depending on the jurisdiction these first responders may be emergency medical technicians, police or firefighters. In some cases it may be a succession of these groups, depending on who can be on the scene first vs. who has appropriate medical equipment and training. Their job is to assess the situation, provide emergency medical intervention and, in some jurisdictions, even if the child is dead, transport the child to the hospital emergency department. Both families and providers may suffer when these personnel have no knowledge of cultural differences in response to trauma and grief, when the workforce does not reflect the diversity of the community served, and when there is no mechanism to assure that families and responders can communicate effectively.

To facilitate cultural and linguistic competence in the first response, each of the agencies and the consortium of all agencies involved should consider the following policies:

- A mission statement that articulates its principles, rationale and values for culturally and linguistically competent services.
- Structures to assure for diverse consumer and community participation in the planning, delivery and evaluation of its services.
- Policies and procedures for staff recruitment and retention to achieve a culturally and linguistically competent workforce that reflects the diversity of the community served. If workforce diversity is not yet achieved, a process for partnering with community-based organizations to include members of diverse communities in supporting the first response process.
- Policies and resources to support ongoing professional development and in-service training at all levels (management, responders, dispatchers, etc.) in cultural and linguistic competence.
- Written protocols for responding to a death scene that assures interactions with all families are sensitive and supportive.
- Policies, procedures and fiscal planning for the provision of interpretation and translation services.
- Policies for and procedures to periodically review current practices and new needs due to demographic changes in the community.

2. Hospital emergency departments: If the child is transported to the hospital, families and caregivers will encounter numerous other professionals—nurses, technicians, physicians, admissions clerks, social workers and others. The family may have to repeat all the information given to the first responders, deal with bureaucratic issues such as insurance, and hear devastating news from people who are most likely strangers to them. Although difficult within the busy atmosphere of an emergency room, cultural beliefs and practices related to death must be honored to support families. For families who have limited English proficiency lack of interpreters to help them understand what is happening and lack of translated forms that require their signature add immeasurably to the trauma.

To facilitate the cultural and linguistic competency of emergency departments, hospitals should consider the following:

- A mission statement that articulates its principles, rationale and values for culturally and linguistically competent services.
- Structures to assure for diverse consumer and community participation on planning, advisory and/or community boards.
- Policies and procedures for staff recruitment and retention to achieve a culturally and linguistically competent workforce that reflects the diversity of the community served. If workforce diversity is not yet achieved, a process for partnering with community-based and faith-based organizations to assure that the hospital chaplains and support professionals can tap appropriate assistance for families in the emergency room.
- Policies and resources to support ongoing professional development and in-service training at all levels (management, administrators, admissions clerks, physicians, nurses, technicians, chaplains, social workers, etc.) for culturally competent values, principles and practices.
- Policies, procedures and fiscal planning for the provision of interpretation and translation services as required by accreditation bodies, the Hill-Burton Act and Title VI of the Civil Rights Act.
- Policies for and procedures to periodically review current practices and new needs due to demographic changes in the community.

A mother whose infant died of SIDS remembers:

“There were six police cars parked outside my house. The ambulance was there and the fire truck that arrived first. Later in the day the coroner’s car showed up and another police car. All those people were overwhelming. But worst of all—just at the time when I needed all the support I could get, my neighbors started ignoring me. They thought we had murdered our baby.”

3. Investigators/community improvement processes: When there is a sudden, unexpected death at a home or child care setting, an investigation into the cause of death is required. Thus, families and caregivers will encounter death scene investigators which, depending on the jurisdiction, may include police or sheriff’s office personnel and/or coroner/medical examiners’ office personnel. These groups assess the data to establish the cause of death and whether there is any criminal action involved.

A second type of investigation may also be required to determine if deficiencies in the infant’s care led to the death. In this case, child welfare agency personnel and, if the death took place in a child care setting, child care licensing agency personnel may also conduct investigations. In these instances, those who are grieving also must deal with the stress of being assessed for possible blame in the death of the infant. For members of some racial or ethnic groups, the usual strains of dealing with the investigation process can be intensified by issues

such as historical mistrust of law enforcement and government, fears related to being undocumented immigrants, traumatic experiences with law enforcement in their home countries or being targeted for more rigorous investigation due to prejudice relating to race, ethnicity or economic status (Lane, et.al., 2002). Finally, in communities that have a FIMR process, families may be asked to be interviewed several months later to help the community understand the factors that led to the infant's death.

To facilitate cultural and linguistic competency in investigatory or information gathering interactions with families and caregivers, agencies and coalitions should consider the following:

- Policies and procedures for staff recruitment and retention to achieve a culturally and linguistically competent workforce that reflects the diversity of the community served.
- Policies and resources to support ongoing professional development and in-service training at all levels (management, administrators, death scene investigators, case workers, etc.) for culturally competent values, principles and practices. Such training should include content that assure sensitivity to families needs, knowledge about diverse responses to grief, culturally based health and child care practices and potential biases.
- Policies and procedures that utilize cultural brokers from the community to review tools and questionnaires, as well as the investigation process, to assure sensitivity and appropriateness in interactions with diverse families and caregivers.
- Policies, procedures and fiscal planning for the provision of: 1) interpretation services with personnel who are trained in the investigation process and who can assist families and caregivers understand the process and their rights; and 2) translation of any documents which families and caregivers must complete, approve or sign.

4. Bereavement support providers: In communities with an effective system to support families and caregivers who have had a sudden and unexpected loss of an infant, families will have options for the type of support they receive. Choices might include intermediate supports provided by hospital social workers or grief counselors, funeral directors, clergy/spiritual leaders; and long-term bereavement support provided by public agencies, professionals or peer family groups. Families may also turn to medical professionals to support them in decisions about future child bearing. Families may choose not to pursue supports that do not mesh with and respect their cultural beliefs and values or are not in their language (U.S. Committee on Refugees, 2002). Lack of bereavement support can then exacerbate the long-term psychological impact of the sudden and unexpected loss of a child (Shapiro, 1994). To facilitate culturally and linguistically competent bereavement services, organizations and professionals should consider the following:

- Policies and resources to support ongoing professional development and in-service training for all staff on cross-cultural communication and working in cross-cultural situations.
- Policies, procedures and fiscal planning for the provision of services in the language preferred by the family. These should assure that written forms (including those used by funeral directors) and support materials are appropriate in literacy level, language and cultural content for the families and caregivers served.
- Policies, structures and resources that facilitate outreach and collaboration with community organizations and natural support networks to assist in the provision of sensitive and appropriate bereavement support.
- Policies and procedures for staff and volunteer recruitment and retention to achieve a culturally and linguistically competent workforce that reflects the diversity of the community served. If diversity is not yet achieved, mechanisms should be instituted for working with cultural brokers in the diverse communities served to help accomplish that goal.

5. Community collaborative teams: An integrated community approach is necessary given the number of systems, agencies and providers encountered by families and caregivers after the sudden and unexpected death of an infant. Community capacity to integrate culturally and linguistically competent approaches is essential.

Teams or coalitions, such as FIMRs or Healthy Start Coalitions, offer the opportunity to work community-wide toward cultural and linguistic competence in the following ways:

- Track community demographics to identify new or emerging populations.
- Create policies and procedures to support sharing resources for interpretation and translation services.
- Create structures and procedures to conduct, offer or provide co-training and cross-training opportunities related to cultural and linguistic competence among community agencies and providers.
- Structure opportunities to create partnerships with community organizations and leaders within diverse communities to guide and inform community response to sudden and unexpected infant death.
- Create policies and procedures to ensure that all families who experience sudden and unexpected infant death are systematically offered a range of culturally and linguistically competent supports.

Programs and providers whose service area includes American Indians/Native Americans or Native Alaskans on lands under tribal jurisdiction, will need to understand and be able to collaborate effectively with different, additional system of services. In some states, SIDS related services are linked to programs and funding streams that are connected to state or local health departments. These programs may or may not apply to American Indians/Native Americans and Native Alaskans living on lands under tribal jurisdiction. In these areas (e.g., reservations, trust lands, etc.) there may be whole separate tribal systems of law enforcement, courts, health services and social services that must be engaged in the process of responding to the sudden and unexpected death of an infant. Most do not have coroners or medical examiners and may, or may not, be required to report these deaths to a state or county official for determination of cause of death and for any connections to support services. In some tribal areas, the Indian Health Service, which is federally managed and staffed by federal employees, will be the source of health services. In other areas, health services are fully owned and managed by tribes, and the Indian Health Service serves as a resource and provider of technical assistance. It is vital to learn about the tribal systems in any locality and to extend opportunities to them to collaborate in serving families and caregivers.

Linking Policy and Practice

A number of organizations have developed **practice** guidelines for the various systems addressed in this Policy Brief. Some, including the Association of SIDS and Infant Mortality Programs (<http://www.asip1.org>). The National SIDS and Infant Death Program Support Center (<http://sids-id-psc.org>), and the National Fetal and Infant Mortality Review Program (through the website of the American College of Obstetricians and Gynecologists at <http://www.acog.org>) have developed practice guidelines that include approaches to working with diverse families. Such resources can be used in conjunction with this document to look at both the policy and practice levels within organizations. Ensuring that culturally and linguistically competent practice is institutionalized and evaluated in an ongoing way, however, requires the establishment and review of policies as described in this document.

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About the



National
Center
for
Cultural
Competence

The mission of the National Center for Cultural Competence (NCCC) is to increase the capacity of health care and mental health programs to design, implement and evaluate culturally and linguistically competent service delivery systems. The NCCC conducts an array of activities to fulfill its mission including: (1) training, technical assistance and consultation; (2) networking, linkages and information exchange; and (3) knowledge and product development and dissemination. Major emphasis is placed on policy development, assistance in conducting cultural competence organizational self-assessments, and strategic approaches to the systematic incorporation of culturally competent values, policy, structures and practices within organizations.

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