Association of SIDS and Infant Mortality Programs

Confronting the tragedy of infant and child death through counseling, education, advocacy, and research

THE UNEXPECTED DEATH OF AN INFANT OR CHILD: STANDARDS FOR SERVICES TO FAMILIES

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ASIP **Association of SIDS and Infant Mortality Programs**

Confronting the tragedy of infant and child death through counseling, education, advocacy, and research

The Association of SIDS and Infant Mortality Programs (ASIP) is an association of health and human service professionals committed to bereavement support and risk reduction activities. ASIP promotes programs of counseling, education, advocacy, and research to ensure a supportive community response for those affected by infant and child death and to reduce the risk of death for future children.

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ASIP members are available to assist individuals interested in implementing these standards. For more information or to request additional copies, please contact our national office at (612) 813-6285.

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THE UNEXPECTED DEATH OF AN INFANT OR CHILD:
STANDARDS FOR SERVICES TO FAMILIES

Introduction

In the United States, approximately 28,000 infants and 13,000 children died in 1998. The leading cause of death for children is accidents and adverse actions, whereas Sudden Infant Death Syndrome is the leading cause of death for infants from one month to one year of age. The death of any child constitutes a crisis for the family and community. An unexpected death, however, poses unique challenges. When unexpected death occurs, families are generally not engaged in a bereavement service delivery system. They may not know how to access such services, or may be too overwhelmed and traumatized to do so. In addition, responsibility for diagnosing the cause of unexpected deaths is in the medical/legal jurisdiction of the medical examiner/coroner system, which is unfamiliar to most families. Some families, including those from culturally diverse backgrounds, may have a distrust of legal and law enforcement systems. This distrust may be based on a historical perspective as well as their own experiences.

The sudden death of a child is a tragedy and a trauma, which confronts families, communities and service providers. Extending care and support to bereaved families immediately following the death of a child is essential to facilitating the healthy resolution of their grief and bereavement. Many health and human service agencies and professionals are involved in this effort.

The *Standards for Services to Families* is designed to be a resource to professionals as they assist bereaved individuals and their communities to cope with infant and child deaths. This document identifies twelve standards, which can guide service systems, public health agencies, and community programs to develop high quality programs that provide appropriate bereavement support and risk reduction services. The *Standards* emphasize that programs and services must be designed and provided in a manner that is sensitive, culturally competent, linguistically appropriate, and consistent with the cultural beliefs, values, and practices of the families and communities served. They are designed as a model of service for any community or region. States or localities with comprehensive programs may implement all of the standards, whereas other may choose to use only selected standards according to the scope of their programs.

This document includes appendices to provide supplemental information about bereavement services and case management. Appendix A presents a historical perspective of family bereavement support and the Association of SIDS and Infant Mortality Programs (ASIP). Appendix B illustrates one model of case management as developed by the Massachusetts Sudden Infant Death Program. Appendix C describes an ASIP intervention model for professional case management of unexpected child and infant deaths. Appendix D offers a definition of cultural competence as set forth by the Maternal and Child Health Bureau.

THE UNEXPECTED DEATH OF AN INFANT OR CHILD: STANDARDS FOR SERVICES TO FAMILIES

STANDARD 1: ***A designated program will provide professional case management, counseling, and support services to help bereaved families cope with the sudden, unexpected death of an infant or child.***

STANDARD 2: ***First responders (i.e., law enforcement, fire, ambulance personnel) will be knowledgeable of sudden infant and child death and possess the necessary skills to respond in a supportive, culturally competent manner to families who have experienced a sudden, unexpected death.***

STANDARD 3: ***Hospital emergency department personnel will respond appropriately to the infant and child's final needs.***

STANDARD 4: ***Hospital emergency department personnel will respond in a supportive manner to families.***

STANDARD 5: ***Investigative personnel will gather information in a manner supportive to families as they assist authorities responsible for determining the cause of death.***

STANDARD 6: ***Coroners or Medical Examiners will conduct the death investigation in a manner consistent with standard protocol, have knowledge about causes of unexpected infant and child death and demonstrate sensitivity to their role in addressing family needs.***

STANDARD 7: ***Spiritual advisors*** **and** ***funeral directors will assist the family in planning services for the infant or child consistent with the religious beliefs and customs of the family.***

STANDARD 8: ***Families will receive a crisis call within 24 to 48 hours after the death, and offered (where available) a home visit by a Community Health Nurse, Social Worker, other trained professional, or trained community outreach worker 1-2 weeks after the death. Four follow-up counseling contacts will be offered during the first year after the death.***

STANDARD 9: ***Peer support will be offered to each family who has a sudden infant or child death.***

STANDARD 10: ***The unexpected infant and child death program will provide appropriate information and counseling to extended family, child care providers, and co-workers.***

STANDARD 11: ***The unexpected infant and child death program will use a variety of strategies to promote infant and child mortality risk reduction messages to the community in a culturally and linguistically competent manner.***

STANDARD 12: ***Critical incident stress debriefing is a process that should be available to all individuals involved with or affected by the death of an infant or child, including mortality review participants.***

STANDARD 1: ***A designated program will provide professional case management, counseling, and support services to help bereaved families cope with the sudden, unexpected death of an infant or child.***

Interpretation: Within an identified geographic area, a designated program for unexpected infant and child death will provide professional case management, counseling, advocacy, and support services to families. The professional staff of the program will assure that quality, culturally competent, linguistically appropriate services are offered to bereaved families.

The program will be responsible for monitoring and training professional staff, peers, and volunteers who make contacts with families, and for assuring that program policies support the incorporation of cultural and linguistic competence.

Professional program staff will provide ongoing consultation, support, and technical assistance to personnel working with families who have experienced the death of a child. This includes education for caregivers and health care providers as well as community awareness programs to promote better understanding and support for families.

To assure delivery of culturally competent services, programs should include cultural and linguistic differences of the population served.

The program will collect and distribute uniform data concerning the deaths reported to it.

Programs will support and encourage research into the causes of infant mortality as well as the psychcosocial aspects of family coping.

The designated program will monitor compliance with the standards set forth in this document through an ongoing evaluation process.

STANDARD 2: ***First responders (i.e., law enforcement, fire, ambulance personnel) will be knowledgeable of sudden infant and child death and possess the necessary skills to respond in a supportive, culturally competent manner to families who have experienced a sudden, unexpected death.***

Interpretation: The reactions of the first responder can have a significant impact on the later adjustment of families to the death. First responders should, as a matter of policy, receive training about the cultural beliefs, values and practices in relation to an infant or child's death that may commonly be held in the communities they serve.

The first responder will be familiar with the statistics, epidemiology, typical history, and current proposed etiologies of sudden infant and child death.

The role of the first responder is to perform an assessment, care for the infant/child, and initiate CPR based on local protocol.

Emergency responders care for the infant/child, observe the scene, document their observations, transport, and provide emotional support to the family.

If the infant or child is pronounced dead at home and not transported to the hospital, the family will be offered the opportunity to see, touch, and hold their infant/child or to perform other actions to express their feelings in an unhurried, sensitive manner that is in keeping with the cultural beliefs, values and practices of the family.

First responders provide leadership and protection to the family when they arrive at the scene. Their role requires cultural sensitivity and knowledge of the scope of family grief reactions, which may range from numbness or no apparent reaction to hysteria.

Responders will be sensitive when making inquiries about the health history, accepting of parents' feelings, and nonjudgmental about physical conditions of the home.

They will assist in arranging care of children remaining in the home.

They will allow parents to accompany their child to the hospital or arrange other transportation for them.

STANDARD 3: ***Hospital emergency department personnel will respond appropriately to the infant and child's final needs.***

Interpretation: Emergency life-saving care will be provided as dictated by protocol. A full medical and health history will be documented. This will include the essential information regarding the birth, medical care, recent illnesses, and the child's activity during the preceding 24 hours.

The autopsy request will be handled as dictated by local jurisdictions. Staff will convey the advisability of an autopsy to the parents. Personnel will be aware that an autopsy, death scene investigation, and previous medical history are necessary to determine the cause and manner of death and that these activities are in the jurisdiction of the local medical examiner/coroner.

Hospital emergency personnel will receive training on the cultural issues related to autopsy for the communities they serve. The use of cultural brokers who can support families in decision-making around an autopsy should be promoted. When autopsy is mandatory, support from such cultural brokers should be provided to help families deal with the distress of having to break with cultural beliefs, values and practices.

STANDARD 4: *Hospital emergency department personnel will respond in a supportive manner to families.*

Interpretation: Hospital personnel will assist in notification of essential family members as identified by the parents and facilitate their transportation to the hospital.

Information concerning the child's condition will be given in a frequent and consistent manner.

If possible, a private place for the family will be made available. Family members will be supported in addressing their grief in a manner that is culturally and linguistically competent.

The use of sedatives and tranquilizers will be carefully evaluated since they are rarely needed.

The family will be offered the opportunity to see, touch, and hold their infant/child or to perform other actions to express their feelings in an unhurried, sensitive manner that is in keeping with their cultural beliefs, values and practices.

Emergency room personnel will notify the local medical examiner/ coroner, health care provider and the local unexpected infant and child death program of the death.

STANDARD 5: *Investigative personnel will gather information in a manner supportive to families as they assist authorities responsible for determining the cause of death.*

Interpretation: Investigative personnel will understand the range of causes of sudden death in infants and children, e.g., SIDS, infections and other natural causes, accidents, abuse, and neglect. Investigation of sudden death will be based on a protocol that does not presume any of these possible etiologies.

Investigative personnel will conduct the death investigation in a non-threatening manner with special understanding that some families may have a distrust of legal and law enforcement systems.

Investigative personnel should provide trained interpreters for families with limited English proficiency.

Victim assistance will include arrangements for care of minors present at the scene, securing the premises, and transporting parents to the hospital. Parents will not be detained at the scene unless evidence indicates the possibility of foul play or that such detention is necessary for the investigation process.

Investigative personnel will be knowledgeable of the scope of family grief reactions, which may range from numbness, or no apparent reaction, to hysteria. Their role requires sensitivity in making inquiries about the baby's health, acceptance of parents' feelings, and a nonjudgmental approach about physical conditions of the house.

All members of the investigative team should receive training in the area of cultural and linguistic competence, including approaches for culturally competent interviewing.

STANDARD 6: ***Coroners or Medical Examiners will conduct the death investigation in a manner consistent with standard protocol, have knowledge about causes of unexpected infant and child death and demonstrate sensitivity to their role in addressing family needs.***

Interpretation: Diagnosis of the cause and manner of death will be based on a comprehensive autopsy, a death scene investigation, and the child's prior medical history.

Coroners/Medical Examiners will be informed about the cultural and religious implications of autopsy for communities in their jurisdictions.

The Coroner/Medical Examiner will facilitate prompt parental notification of the preliminary autopsy findings within 24 hours of the death and the final diagnosis within 24 to 48 hours after final determination of the cause of death.

Coroners/Medical Examiners will interact with families in a supportive, culturally appropriate, sensitive manner that encourages parents to ask questions and to discuss their concerns.

Coroners/Medical Examiners will know the range of emotional reactions of bereaved family members and respond appropriately.

Coroners/Medical Examiners will refer families to appropriate, culturally competent bereavement support services.

STANDARD 7: ***Spiritual advisors*** **and** ***funeral directors will assist the family in planning services for the infant or child consistent with the religious beliefs and customs of the family.***

Interpretation: Funeral rituals can be a significant therapeutic and healing experience for the family. The funeral director will inform families of burial and service options. A variety of options should be available to ensure that services are sensitive, culturally competent, linguistically appropriate, and consistent with the cultural beliefs, values, and practices of the bereaved family.

Spiritual advisors and funeral directors will be well informed of the cultural issues surrounding the death of a child, mourning practices, funeral rituals etc. for the communities they serve and will be prepared to respond appropriately.

The spiritual advisor and funeral director will ask the bereaved family to identify those whom they would like to include in planning and participating in the funeral rituals.

The funeral director will invite families to participate, as much or as little as they would like, in activities such as dressing, bathing and/or holding their child for as long as necessary.

Spiritual advisors and funeral directors will encourage families to perform their own personal ceremonies or rituals that are in keeping with their cultural beliefs, values and practices.

The spiritual advisor and funeral director will allow families to express their feelings in an unhurried, sensitive manner.

The family's spiritual advisor can provide counseling, support, and advocacy.

STANDARD 8: ***Families will receive a crisis call within 24 to 48 hours after the death, and offered (where available) a home visit by a Community Health Nurse, Social Worker, other trained professional, or trained community outreach worker 1-2 weeks after the death. Four follow-up counseling contacts will be offered during the first year after the death.***

Interpretation: Support services will assist bereaved families to cope with intense emotional reactions, physical illness, and severe family stress that are often experienced after the death.

The objectives of intervention are to provide accurate information to the family about the cause of death, to offer anticipatory guidance about the grief experience, and to introduce them to a range of available support services. Discussion of children's reactions and suggestions for parental support of surviving children also are included in these first contacts.

Health care/human services professionals providing services will be trained in the cultural beliefs, values and practices in relation to an infant or child's death that may commonly be held in the communities they serve. The provider will be knowledgeable of community resources, including natural support networks and be fluent in the family's preferred language, or prepared to work with a trained interpreter.

An ongoing assessment of the family's reaction to the death will be made and appropriate services offered. Services may include mental health programs, peer-to-peer support, and self-help group.

Health care/human services professionals will assure that families are linked with reproductive health care providers to promote the health of subsequent child.

Services will be available and outreach made for a minimum of one year to adequately respond to the period of bereavement and resolution.

A well-trained health care/human services provider who is knowledgeable of these issues and resources is critical for effective intervention.

STANDARD 9: ***Peer support will be offered to each family who has a sudden infant or child death.***

Interpretation: Peer support can provide people in similar circumstances an opportunity to share their unique experience and their approaches to coping with the death of a child. The unexpected infant and child death program will include a peer support component or will collaborate with a peer support program to ensure that peer support is effective and available to all families.

The infant and child death program and the peer support program will offer the opportunity for individual peer support to each family but will be aware that some families may not view the death of a child as placing them in the same peer group.

Peer support providers are a minimum of one year beyond their own infant/child death experience.

Peer support providers will be trained in such areas as the range of causes of infant mortality, normal and complicated grief, qualities and limitations of a helping relationship, referral resources, reporting responsibilities, and cultural and linguistic competence.

STANDARD 10: ***The unexpected infant and child death program will provide appropriate information and counseling to extended family, child care providers, and co-workers.***

Interpretation: Services offered to families who have experienced an infant or child death also will be available to extended family, child care providers, and co-workers. All services will be culturally and linguistically appropriate for the individuals being served.

The emotional reaction of these individuals may be intense and require crisis intervention, anticipatory guidance about the grief experience, and assistance with responding to the bereaved family.

Individuals will be encouraged to express their feelings in an unhurried, sensitive manner that is in keeping with their cultural beliefs, values and practices.

STANDARD 11: ***The unexpected infant and child death program will use a variety of strategies to promote infant and child mortality risk reduction messages to the community in a culturally and linguistically competent manner.***

Interpretation: Public awareness of risk reduction messages such as infant sleep position, safe bedding, safe sleep environment and other information about best infant and child care practices is necessary to decrease deaths.

The program and/or other public health agency will coordinate the effort to disseminate risk reduction messages. This can be an effective means to assure that all members of the community receive appropriate information.

Programs/agencies will partner with community organizations that represent the targeted populations when possible**.**

Each community should determine the method of message delivery to ensure that it is culturally and linguistically appropriate.

Target populations include new and expectant parents, grandparents, child care providers, other caregivers, and communities with higher risk for infant mortality.

STANDARD 12: ***Critical incident stress debriefing is a process that should be available to all individuals involved with or affected by the death of an infant or child, including mortality review participants.***

Interpretation: The death of an infant or child is a tragedy that touches the entire community. Frequently, the first responders, emergency department personnel, and investigative personnel are deeply affected as they process their work with the infant/child and family and may experience an acute or delayed stress response to the event.

Fetal, infant, and child mortality committee members who review the information on fatalities in their jurisdiction may experience feelings of sadness and loss as a result of being consistently exposed to information on each fatality.

Cumulative incident stress can create negative consequences in work, home, relationships, etc.

Critical incident stress debriefing (CISD) is a system that supports the healthy resolution of this tragedy and creates the opportunity to reduce and manage the effects of cumulative stress.

All individuals involved in the event or reviews are encouraged to participate in this process.

APPENDIX A:

Historical Perspective of Sudden Infant Death Syndrome and the Association of SIDS and Infant Mortality Programs (ASIP)

As early as the 1950s researchers were interested in the phenomenon of "crib death", but it was not until the 1960s that an organized effort emerged which addressed the many problems caused by sudden infant death syndrome (SIDS). Organizations were formed to provide parent-to-parent support, group meetings, informational materials, and offered bereaved parents the opportunity to become involved in SIDS related activities. In the United States, these organizations were instrumental in bringing together others interested in spearheading the movement to demand a congressional response to SIDS and the many issues such a death evokes. As a result, congressional hearings were conducted in 1972 and 1973. The testimony documented numerous problems caused by a lack of information, inappropriate case management by professionals and the community, and the emotional morbidity and personal toll of complicated grief. In 1974, the SIDS Act was passed, allocating research monies to study possible causes and mandating sensitive and humane care for those affected by SIDS. To that end, the following objectives were established:

- To conduct post-mortem examinations including autopsies for all cases of sudden and unexpected deaths of infants;
- To use SIDS as a cause of death when appropriate;
- To notify parents of the preliminary cause of death, preferably within 24-48 hours of death;
- To provide counseling for families bereaved by the sudden and unexpected loss of their infants;
- To conduct educational programs for health care providers, funeral directors, clergy, public safety officials, and the public;
- To collect, analyze, and furnish information relating to SIDS.

The Department of Health Education and Welfare (HEW), Division of Maternal and Child Health (MCH), was given the responsibility for implementing these objectives. A model for information and counseling projects was developed, and requests for proposals to establish SIDS projects were announced. By 1975, twenty-four projects had been awarded grants.

Until the 1980s, HEW (now Health and Human Services [HHS]), was directly responsible for providing supervision and support to the SIDS projects. A support/oversight team was available at HEW, and several support services were provided. These included: annual conferences for all individuals involved in SIDS activities, conferences to address special needs (e.g. mental health issues), and audio-visual and printed materials for educational purposes. The National SIDS Resource Center was established, and studies were conducted to evaluate, improve, and better coordinate the services provided by the projects and peer support organizations.

Following the federal government's consolidation of funding for MCH categorical programs in the early 1980s, funds were given to each state in a "block grant". The block grant allowed each state to decide how it would allocate these funds. As a result, some states drastically reduced or totally discontinued funds for their SIDS programs. Other states expanded their programs by making them responsible for providing support services to families, but did not increase funding accordingly.

The 46 federally financed programs that existed in the mid-1970s shrank to approximately 20 by 1988. During this time, the federal government continued to fund the National SIDS Resource Center, but other federal support services were cut back to one part-time support position and a few small grants for selected special needs. In response to these developments, some of the stronger state programs reorganized. Several programs became independent nonprofits while others merged with a peer support organization. Most programs began raising their own funds, and many expanded their focus to support all families whose infant had died suddenly.

It became increasingly apparent that without a central organizing and communication source, professional SIDS resources would become more fragmented and, in many cases, would cease entirely. Thus, in 1987 the **Association of SIDS Program Professionals (ASPP)** was established to help fill the gap left by the government's withdrawal. The ASPP represented health and human service professionals who provided services to nearly 4,000 families each year who experienced the death of a child due to SIDS. In 1996, the organization changed its name to the **Association of SIDS and Infant Mortality Programs (ASIP)** to reflect the expansion of services to broad-based bereavement support and training. In addition to information and counseling, ASIP members participate in research and provide professional and community education, peer support, advocacy, training, and consultation services that link health departments, emergency responders, medical examiners, coroners, law enforcement, health and mental health professionals across the country.

The objectives originally established by the SIDS Act in 1974 are still valid as we enter the new millennium. SIDS continues to be the leading cause of death in infants from one month to one year of age. With the United States ranked 26th (1998) for infant mortality among industrialized nations, infant mortality is a significant national issue. Bereaved parents require compassion and support to heal as a family and as individuals. The overall goal is to ensure that those affected by SIDS and other causes of infant mortality receive immediate, sensitive, and humane care and accurate information.

In March 2000, ASIP and the Maternal and Child Health Bureau partnered to sponsor an invitational meeting to develop recommendations for expanding program services. Participants made many significant recommendations, including: a core set of bereavement and risk reduction services should be provided; services should be accessible to all families who experience the death of a child from twenty weeks of gestation to two years of age; effective services must be culturally competent and sensitive to the family's belief system. The *Unexpected Death of an Infant or Child*: *Standards for Services to Families* is designed as a model of service for any community or region. States or localities with comprehensive programs may implement all of the standards, whereas other may choose to use only selected standards according to the scope of their programs.

APPENDIX B:

Case Management of Infant and Child Deaths: A Profile Revisited

By: Mary McClain R.N., M.S., Coordinator, Massachusetts Center for Sudden Infant Death Syndrome, Massachusetts Child Death Bereavement Program

The Massachusetts Center for Sudden Infant Death Syndrome (SIDS) is responsible for coordinating services to families whose children die of sudden infant death syndrome and other causes of infant mortality (0-3 years). Funded originally by the SIDS Act of 1974 and subsequently through block grants and private fund raising, the Center has pursued its primary mission of ascertaining the cause of death in sudden infant mortality, notifying parents of the medical findings, and offering support to family members during their bereavement.

The Center's statewide services include: crisis contact within 24 - 48 hours of referral, 7 day per week, 24 hour per day counseling by medical doctors and the SIDS nurse coordinator, regular follow up by community health nurses, support group meetings, and parent to parent contact. Other services include the provision of educational materials and seminars, as well as compilation of epidemiological data for the Massachusetts Department of Public Health.

Initial Care and Follow-up

When an unresponsive infant is brought to the emergency room of a hospital, a set of guidelines is recommended by the Massachusetts SIDS Center to all emergency staff. The child is examined and resuscitation initiated or continued while the parents are provided a private space. An attending nurse or social worker informs the parents about their child's condition. When the mother and father are informed of their child's death, emergency staff offers immediate emotional support and encourage parents to see and hold their child. Before parents leave the hospital, staff ascertains where and how they can be contacted in the immediate future.

The SIDS Center receives notification of the child's death from the medical examiner, hospital, pediatrician, family member and parents themselves. Telephone contact is made by Center staff with the family within 24-48 hours to provide crisis counseling, preliminary autopsy information, and notification that a SIDS counselor will call to schedule a home visit. A condolence letter is sent to the family with brochures and other information about the cause of death and the grieving process. All families are informed of parent support group meetings, the availability of a parent contact and referral to the Massachusetts Chapter of the SIDS Alliance. Support groups are emphasized because they provide a nurturing environment in which parents can express their feelings, meet other grieving parents, and receive reliable information.

The Center notifies the baby's pediatrician of the death, informs him/her that the Center will be providing services to the family, describes what those services include, and often provides updated information on SIDS and professional support as well.

Continuing Care

The professional nurse counselor or social worker is responsible for providing care to the bereaved family. The overall goal of counseling is to mobilize the strengths of the family to assimilate the loss of the baby in a way that allows family members to continue to function and to recognize that life is worth living and happiness is possible.

More than 40 agencies and 100 community health nurses contract with the Massachusetts Center to provide follow-up to families during the first year of bereavement. Through the nursing process-assessment, intervention, and evaluation - the nurse designs a plan of care with each family. During family meetings, the nurse presents accurate information about the cause of death; provides anticipatory guidance regarding the grieving process; evaluates each family member's response to the death; assesses social support systems; informs the family of available resources; obtains medical information for the Center's statistical data base; and reviews written autopsy reports. The nurse provides continued care through home visit and telephone contact during the first year of bereavement and beyond.

Culturally Competent Services

Community health nurses who provide bereavement counseling are of various racial and ethnic backgrounds including African-American, Haitian, Latino, Portuguese, West Indian and Cape Verdean. Center staff train nurses who are fluent in Spanish, Haitian, French Creole, Portuguese and French. These training programs include information on cultural awareness and sensitivity as well as cultural beliefs regarding death, dying and bereavement. Appropriate bereavement follow-up is enhanced with the assistance of qualified interpreters.

Center director, Dr. Frederick Mandell has developed an award winning culturally sensitive SIDS brochure for American Indian families. Dr. Mandell and Center Coordinator, Mary McClain conduct training workshops on SIDS for members of Indian tribes on reservations in North and South Dakota, and for the Aberdeen Area Indian Health Service. Coordinator, Mary McClain has experience in developing and implementing training programs for community health nurses in transcultural nursing care.

Professional Education and Training

Education prepares professionals and community members to respond appropriately when an infant or child dies suddenly and unexpectedly. Educational programs conducted by the Center provide physicians and nurses, emergency responders, police officers, hospital emergency department personnel, child care providers, funeral directors, medical examiners, clergy, social workers, students and lay persons with information to assist them in supporting families who have experienced the tragedy of infant or child death.

The Center provides training, consultation, and professional support for the nurses who provide home visiting and bereavement support for affected families. The Center publishes a semi-annual newsletter, guidelines for hospital emergency department personnel, a nurse counselor training manual and several brochures.

Data Management and Reporting

The SIDS Center utilizes a computer based database management system and data collection forms that are utilized to compile data and perform statistical analyses. The Center collects medical and demographic data for the population served, as well as data which summarizes the services provided by the Center. This data management system enables the Center to provide timely reports of its activities and to maintain a database of potential value for SIDS research.

Parent Support Groups

Center staff facilitates support groups for bereaved parents, which meet monthly in three locations. These support groups aid in the resolution of the early trauma of grief experienced by parents following the sudden unexpected death of their infant or young child. Parents need to talk about their baby. They need to talk about the events of his/her life as well as death, feelings related to their own grieving, reactions of other children, and concerns about subsequent children. The support group provides:

_ A safe environment for parents to express their feelings
_ A reliable source of information about SIDS and other causes of infant death
_ The opportunity to help others

Any parent experiencing a sudden infant death is welcome, as are grandparents, siblings, extended family members, friends, and caregivers. No registration is required, and there is no fee.

Peer Contact

Upon request, the Center matches newly bereaved families with a peer contact. Center staff train and supervise peer contacts who are at least one year removed from the child's death. Peer contacts are parents, grandparents and child care providers who provide a network of support to bereaved families. When possible, contacts are matched with families according to demographic characteristics and circumstance of death. Peer contacts are accountable to the SIDS Center regarding their intervention with families.

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APPENDIX C:

Professional Case Management: An ASIP Model

The following is an outline of an intervention model for professional case management of individual unexpected infant/child deaths. This model describes the timing of the contacts and presents the type of interventions to consider at each contact. Intervention must be flexible to meet the needs of each individual family. The outline does not endow the reader with the comprehensive range or depth of skill required to provide quality services.

A. CRISIS CALL — A trained professional makes family contact within 24 hours of referral by telephone or, if no phone, home visit.

_ Offer personal condolences
_ Inform family of cause of death and results of preliminary autopsy findings
_ Discuss immediate questions and concerns
_ Determine funeral/burial plans, need for assistance with plans and/or financial barriers
_ Inquire if there are other immediate needs, i.e., health, family, social, etc.
_ Assess source(s) of support within family network
_ Offer information about needed community services for assistance
_ Inform about availability of peer support and requests consent for peer contact
_ Provide phone numbers for family to contact PHN, hotline, peer support, medical examiner/coroner
_ Make arrangements for the first home visit

B. INITIAL HOME VISITS — Visits within 7 days with as many family members as possible.

_ Express personal condolences
_ Discuss cause of death
_ Answer immediate questions
_ Initiate grief assessment, suicide risk assessment
_ Encourage family members, each from his or her point of view, to re-create the events from before the baby's death up to the present
_ Clarify misconceptions family members may have about the circumstances surrounding the death and about the cause of death
_ Identify areas of perceived self-responsibility and blame. Counter guilt-induced comments or interpretations of events
_ Reinforce parent's competence and parenting skills by highlighting true and positive aspects of the incident, i.e., their handling of the emergency, care of the deceased infant, and concern for and skill with other children

_ Normalize the parent's grief reactions and provide anticipatory guidance
_ Discuss differences in how grief is expressed among family members
_ Assess parental ability to respond to surviving children and bond with them
_ Facilitate mutual support and encourage family communication
_ Provide nonjudgmental listening and express acceptance
_ Review resources i.e. literature, peer contact, support group meeting, and community resources
_ Document strengths, potential risk factors, problem list, interventions, and plans
_ Make arrangements for follow-up visits and inform family of next contact

C. FOLLOW UP HOME VISIT — Visit scheduled approximately 1-2 months after death.

_ Provide information as needed
_ Continue grief assessment
_ Assess coping style since last contact
_ Monitor grief issues, review and update problem list, assess risk
_ Inquire about availability of initial support system identified at time of death
_ Discuss final autopsy results
_ Address perception of benefit if parent has attended a support group; encourage participation if parents have not considered a group
_ Assess necessity of intervention with grandparents, siblings' school, parent's employer, etc.
_ Reinforces competence
_ Facilitate siblings' healthy adaptation
_ Coach parents to ask for what they need from others
_ Facilitate discussion of issues between parents (or relevant family members)
_ Assist with decision-making and the resolution of differences
_ Reinforce parent's reinvestment in life
_ Make referrals for appropriate services as needed.

D. INTERIM HOME VISIT — Visit scheduled approximately 4-6 months after death.

_ Provide information as needed
_ Complete grief assessment
_ Monitor grief issues, review and update problem list, assess risk
_ Assess current status of availability of support systems, expectations of others
_ Inquire how family is managing change of seasons, holidays, special family celebrations, interactions with other infants, possible anniversary of infant's date of birth
_ Offer counseling and support
_ Discuss subsequent pregnancies and related issues

E. ANNIVERSARY HOME VISIT — Visit scheduled 9-12 months after death.

- Provide information as needed
- Assess support systems
- Monitor grief issues, review and update problem list, assess risk
- Discuss and assess parents' perception of change and growth
- Evaluate status to determine if closure is appropriate
- Discuss closure with family, assess dependency issues, encourage us of appropriate supports
- Provide telephone numbers and information so families can have their case re-opened or request additional support

F. CASE CLOSURE — Standard case closure occurs as listed.

- After first anniversary of death if needs are being met and risk factors are resolved
- Upon request of family
- Whereabouts of family is unknown
- Complicated grief situations that are referred to appropriate resources for grief therapy

G. CASES ARE RE-OPENED — Under the circumstances as listed.

- Upon request of family
- Assessment and evaluation indicates support should continue
- Referral from other source

Appendix D:

Maternal and Child Health Bureau

DEFINITION OF CULTURAL COMPETENCY

Cultural competence is defined as a set of values, behaviors, attitudes, and practices within a system, organization, program or among individuals and which enables them to work effectively cross culturally. Further, it refers to the ability to honor and respect the beliefs, language, interpersonal styles and behaviors of individuals and families receiving services, as well as staff who are providing such services. Striving to achieve cultural competence is a dynamic, ongoing, developmental process that requires a long term commitment of time.

At a systems, organizational or program level, cultural competence requires a comprehensive and coordinated plan that includes interventions on levels of: (1) policy making; (2) infrastructure building; (3) program administration and evaluation; (4) the delivery of services and enabling supports; and (5) the individual. This often requires the re-examination of mission statements; policies and procedures; administrative practices; staff recruitment, hiring and retention; professional development and in-service training; translation and interpretation processes; family/professional/community partnerships; health care practices and interventions including addressing racial/ethnic health disparities and access issues; health education and promotion practices/materials; and community and state needs assessment protocols.

At the individual level, this means an examination of one's own attitude and values, and the acquisition of the values, knowledge, skills and attributes that will allow an individual to work appropriately in cross cultural situations.

Cultural competence mandates that organizations, programs and individuals must have the ability to:

1. value diversity and similarities among all peoples;

2. understand and effectively respond to cultural differences;

3. engage in cultural self-assessment at the individual and organizational levels;

4. make adaptations to the delivery of services and enabling supports; and

5. institutionalize cultural knowledge.

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This definition is adapted from:

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Developed by D. Denboba, T. Goode, 5/99.