



**Supporting Families from  
Sudden Infant Death Syndrome (SIDS)  
To Other Infant Death**

Lessons Learned

**Final Report**

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Other Infant Death (ID)  
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# **Supporting Families from Sudden Infant Death Syndrome (SIDS) to Other Infant Death (ID): Lessons Learned**

## **I. Introduction**

Many programs originally designed to provide bereavement support and risk reduction education for parents of infants who died from Sudden Infant Death Syndrome are expanding to provide similar services to families of infants/children who died of other causes. To promote this expansion of services, the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB) sponsored on March 16, 2000, an invitational meeting of SIDS program directors titled, "Other Infant Death – An Evolution of SIDS Programs: A State/Local SIDS and Infant Death Program Perspective," which resulted in recommendations for programs to include other infant deaths (ID) in their mandate. A copy of this report is available from the National SIDS/ID Resource Center located at 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182. The toll free phone number is 1-800-930-SIDS (7437).

HRSA/MCHB commissioned this report, "Supporting Families from SIDS to ID: Lessons Learned," to further explore the needs of programs which were expanding their services, as well as to determine whether there had been lessons learned by some programs that would be helpful to other programs. Two State-level SIDS programs (Massachusetts and Wisconsin) were identified as having implemented specific service expansions for infant deaths from SIDS to other infant and/or child deaths. This summary of the specific services, expansion efforts, challenges and successes of the two identified programs is intended to provide guidance to HRSA in supporting expansion efforts and to other SIDS programs in their future expansion efforts.

## **II. Lessons Learned: Massachusetts Center for SIDS and Infant and Child Death Bereavement Program**

### **Program Origins**

Begun in 1975, the SIDS program at Boston Medical Center (BMC) was one of the original programs funded under the SIDS Act of 1974. The Center is responsible for coordinating services statewide for families whose children die of SIDS or other causes. Services include ascertaining the cause of death in sudden infant or child mortality, notifying parents, providing bereavement support, and training and education for professionals. Major sources of funding for the Center are the Massachusetts Department of Public Health through the Title V Block Grant, private fundraising activities, and contributions.

The expansion of services from SIDS to ID was not a recent one because the program had always provided services for ID. The decision to expand services to support families who experience the loss of a child from fetal demise to 3 years of age was made following an MCHB expansion demonstration grant awarded in 1994.

The Center used an MCHB demonstration grant to expand services to other types of death in Springfield, MA. An important part of the expansion was developing networks in the community for referrals and for risk reduction efforts. Referrals in Springfield came from area hospitals, grassroots community service organizations, and the Medical Examiner's Office. The demonstration was successful because local hospitals realized that the Center could offer additional bereavement support to families whose children had died in hospital settings.

### **Program Implementation and Operation**

SIDS/ID services are available for sudden unexpected deaths of 0-3 year olds. Services are also available for mid to late fetal deaths and for older ages on an individual basis. There are approximately 370 infant deaths each year in Massachusetts, and of these, about 130 are referred to the program. Medical examiners are the primary referral source for the program, followed by hospitals, providers, and families. For families referred to the Center services include:

- contacting the family by telephone after the death of a child
- condolence letter and grief packet sent to family
- referring the family to a community health nurse or social worker trained in bereavement counseling
- providing a home visit to the family by a bereavement nurse or social worker- up to 6 home visits are offered to families in the first year following the death
- data collection by bereavement nurse/social worker which includes circumstances of death, infant and family health history, obstetrical history, and other pertinent information.
- referring the family to a peer support group

- discussing autopsy results with the family
- providing one-to-one peer contact, with peer-parents who are trained by the Center
- facilitating parent support groups
- maintaining contact with the family as needed.

Home visits for grief support are a central component of the program and offered to the family and initiated by family consent. The home visitors are registered nurses who are employees of local home health agencies and are trained by the SIDS program in bereavement and risk reduction education and counseling. Nurses and social workers phone the Center after each initial encounter with a grieving family, and send in written reports as well. The Center receives feedback from families and this was recently used to enhance the training curriculum. Feedback since the training enhancement has been very positive. The Center provides extensive training and education for bereavement counselors, emergency respondents, police cadets, hospital emergency staff, day care providers, and peer support contacts. All training curricula include incidence and causes of infant mortality, racial disparities in infant mortality, epidemiology and research, risk reduction education and grief and bereavement after an infant/child death.

The Center began to focus on women's health prior to pregnancy since it views the chronic ill health of women as a risk factor for infant death, and has developed three brochures as part of a series:

- About feeling and looking good before and after pregnancy
- About your baby
- When a baby dies

These are educational pocket-sized brochures to inform women about health and health care decisions before pregnancy, about infant needs and parenting, and about feelings surrounding the death of a baby. One is available in Spanish. The program is attempting to introduce the concept that women can prepare for pregnancy and that being healthy before the pregnancy is as important as being healthy during the pregnancy.

The Center is part of a community network and has referrals from a wide variety of cultural groups. Cultural sensitivity and competency has always influenced its manner of counseling and providing program services, and the Center provides multi-lingual resources. The Center staff focuses on the beliefs of the parents and understands and respects that every family has its own beliefs about dying and rituals surrounding death. The Center partners with the Boston Public Health Commission, Boston Fetal and Infant Mortality Review, Springfield Department of Public Health, and Springfield's Fetal and Infant Mortality Review to provide bereavement support to families. Center staff is represented at the Massachusetts statewide Child Fatality Review team and on each county review team. The Center works closely with the Massachusetts Department of Public Health to provide training on SIDS and risk reduction education for child care providers.

## **Program Successes and Failures**

The success of the ID program has been based in part on the 1994 MCHB demonstration grant, which provided the funds to adapt the SIDS model to ID, to train providers for ID, to support the development of a broad statewide referral network, and to create and translate brochures. The major limitation of the program in seeking out more referrals has been that it does not have the staff or the financial resources to support more than 160 cases annually. As the Center develops additional resources, it will be more proactive in seeking referrals to support families of infants and children who die in hospitals.

## **Lessons Learned**

The Center believes its SIDS model of support that adapts the dynamics of grief and bereavement to other causes of death can be applied to ID with relatively minor changes. In addition, the following are lessons that the Center has learned:

1. Incorporate and respect cultural perspectives without assuming that heritage alone determines beliefs about death;
2. Evaluate how useful bereavement support services are to families (this can highlight additional needs);
3. Prepare brochures and grief packets, preferably in multiple languages;
4. Be realistic about the scope of services and the number of cases that funding and staff limitations imply; and
5. Be involved in the community to be aware and able to meet its most current needs.

### **III. Lessons Learned - Infant Death Center of Wisconsin**

#### **Program Origins**

The Center for SIDS Counseling and Research began at the Medical College of Wisconsin in 1980. In 1990, Children's Hospital of Wisconsin adopted the program and it became the Wisconsin Sudden Infant Death Center. The program evolved from support to parents of infants who died of SIDS to support for all sudden and unexpected infant deaths, including all infant deaths at Children's Hospital. In 1999 the name changed to the Infant Death Center of Wisconsin in response to feedback from families and referral sources stating the name implied the program was solely SIDS focused. Children's Hospital provides financial support to the program, and wanted to assure that families who experienced infant death at the hospital would have access to the support services. Funding also comes from the Division of Public Health of the State of Wisconsin's Title V Block grant and private contributions.

The Center supports families whose infants die between birth and age 1, which is consistent with the SIDS definition. The Division of Public Health of the State of Wisconsin and Children's Hospital were instrumental in deciding to expand the program to include other infant deaths, but there was no additional funding with the expansion.

#### **Program Implementation and Operation**

The program operates out of a central office at Children's Hospital and three satellite offices across the State using the public health regions as satellite boundaries. This arrangement balances regional needs and statewide coverage with continuity and consistency of services. The Center handles approximately 160 cases per year, the large majority in Milwaukee. These cases come from Children's Hospital's deaths as well as any sudden and unexpected community deaths that are reported to the Center. Anyone can call and receive services. The Center does seek out information on deaths not reported to assure families that fall within the parameters of the program are served. Wisconsin legislation mandates that coroners provide free counseling to families who suffer infant deaths and the Center has worked hard to establish relationships with the coroners and medical examiners who refer cases to them. The collaboration between the Center and Coroner's office also is seen in their participation in local child fatality review teams throughout the state.

The program administrator and a bereavement counselor are in the central office and there are three ½ FTE coordinators assigned to the satellite offices. The coordinators support and train regional public health nurses who provide direct support to families through home visits. For families referred to the Center, services include:

- contacting the family after the death of a child;
- referring the family to a community health nurse;

- providing bereavement support to the family by a professional usually via telephone;
- referring the family to a peer support group;
- discussing autopsy results with the family; providing one-to-one peer contact;
- facilitating parent support groups; and
- maintaining contact with the family as needed.

Specifically:

- A letter of condolence is sent to the family together with information about the Center.
- An introductory call is placed by a counselor.
- A referral to a community health nurse is made, and the public health nurse sets up an appointment with the family.
- The Center also makes regularly scheduled calls to the family.
- The community health nurses offer up to 3 home visits in total providing an epidemiological questionnaire, a family assessment and information on the communities resources, and responding to the family's questions or concerns
- The community health nurses are also responsible for data collection. They try to collect information on the pregnancy, the health of the baby, medical exams, and prenatal care.
- In addition to coordinating the contact between families and support services, and providing training to community health nurses, the Center facilitates memorial events, family conferences and peer support networks. Memorial programs are organized by parents and staff and bring families together biannually to memorialize their child. The Center provides training programs to emergency medical technicians, paramedics, law enforcement, emergency room staff, coroners and medical examiners, funeral directors and others who interact with bereaved families. Topics of these sessions include the dynamics of grief and loss as well as current research on SIDS and risk reduction.

The Center promotes risk reduction efforts with an aggressive public information campaign throughout the State including educational programs for community groups, presentations at health fairs, media interviews, newsletter articles, and training programs. Specific communities with higher than average rates of infant mortality have been targeted for increasing access to risk reduction services and bereavement support. Current partners include the Black Health Coalition, the Latino Health Organization, the March of Dimes, Great Lakes Intertribal Council, the Healthy Start Projects, and the Milwaukee Fetal Infant Mortality Review Project. The Center provides technical assistance to

outreach workers, assists in identifying and serving families, provides services at convenient locations in the community, and has interpreters available for non-English speaking families.

### **Program Successes and Failures**

The program's outreach efforts into the community have been guided by work with community coalitions. These efforts are extensive, but the Center would like to have greater success with risk reduction efforts in communities of color. The Center has spent time cultivating relationships in various communities to increase risk reduction education, and offer services as necessary. The list of current memberships includes: the Steering Committee of the Milwaukee Healthy Beginnings Project, the Milwaukee Fetal Infant Mortality Review Program Case Review Team (FIMR), the African American Infant Mortality Workgroup, and the Honoring Our Children (Native American Healthy Start Project) Consortium.

Brochures and other materials are reviewed by community-based organizations before they are released. The Center is working towards having Spanish translations, and has the use of interpreters through hospitals. The Center also has access to risk reduction and bereavement information in other languages through collaborative relationships and purchases from other organizations.

To improve data collection efforts, a new public health nurse manual was developed and 6 community health nurse training programs were provided throughout the State. The challenge of improving the daytime access of nurses to working families remains.

### **Lessons Learned**

The Center has learned the following lessons:

1. It is important to be flexible and respond rapidly as needs change. For example, when the Center learned that legislation regarding mandated training for childcare providers was about to be implemented, they quickly developed a train-the-trainer curriculum and provider curriculum and provided train-the-trainer programs throughout the State.
2. Family satisfaction surveys can provide a great deal of information on areas that need attention or on the need to assure that services are accessible. It can assist in focusing resources for educational programs as well as assessing if the delivery system needs modification.
3. It is very important to build relationships with the advocacy community. The Center often partners with the March of Dimes, the American Lung Association, and the American Heart Association. They share educational materials for booths at health fairs and share information on their various activities.

4. The specific legislation requiring counseling for parents experiencing an infant death has facilitated the referrals from the medical examiners and coroners offices.

#### **IV. Conclusions**

In a context of relatively small programs with barely adequate funding, some external influence was required to consider expansion in Massachusetts and Wisconsin. In the case of Massachusetts, grant funding for an expansion demonstration in Springfield was essential to gaining the confidence that known resources for SIDS were useful in the context of other infant deaths, and in appropriately adapting these resources for other causes of death. In the case of Wisconsin, the external impetus was the Children's Hospital partnership that required that the Center support other infant death if it occurred in the hospital. Though the State Division of Public Health was encouraging in both cases, they could not provide the additional financial resources required.

The partnerships that both Centers have developed and cultivated are the key to their success in the community because without a network of organizations that can refer families who need services; the Centers would be quite limited in their activities. Each Center has made efforts to constantly assess community needs and find new strategies for meeting them. The balance between seeking out referrals, developing risk reduction programs, supporting bereaved parents, and adapting the program generally to meet new needs is a complex one. It is affected by community needs, referral partnerships, staffing levels, and funding.

For programs to expand to supporting other infant death there must be specific support for the expansion. The current workloads and funding levels usually means that if other infant deaths are referred, they will be supported, but they are not sought out proactively. Both Centers are knowledgeable of the resources available to them, and are committed to providing optimal services to referred families. Due to the decline in the incidence of Sudden Infant Death Syndrome, program expansion to include the provision of services to other infant death is logical. However, increasing the number of families supported, beyond current levels, requires additional resources.

Both Centers noted that they have received strong support from the National Institute of Child Health and Human Development (NICHD), the National Sudden Infant Death Syndrome/Infant Death Resource Center (NSIDRC), the National Center for Cultural Competency (NCCC) SIDS Initiative at Georgetown University, and the Association of SIDS and Infant Mortality Programs (ASIP). Specific examples of the support from these sources are the materials related to the "Back to Sleep" campaign which were provided free of charge by NICHD, and the database template, program evaluation tool, position papers, and standards of care documents that are available through ASIP.

A variety of opportunities to support the expansion to ID exist.

Examples are enumerated below:

- ✓ Providing funding to States for program development to increase bereavement services for new and existing SIDS/OID programs;
- ✓ Collecting, compiling and making available existing infant death and bereavement materials and training curricula to SIDS/OID programs;
- ✓ Providing funding for a key staff person to attend a consultation and training seminar on program development, infant mortality, grief, and bereavement;
- ✓ Providing resources to support statewide Fetal and Infant Mortality Review in States without one;
- ✓ Collect, compile, translate and update central resource materials for risk reduction education for all causes of infant death;
- ✓ Collaborate with other agencies to provide a comprehensive and accessible resource listing;
- ✓ Providing funding for SIDS/OID programs to evaluate their organization and its services;
- ✓ Providing funding and support to evaluate the programs needs and options with respect to data collection, and increase their ability to use the database template created through ASIP;
- ✓ Fostering collaboration between programs through ASIP;
- ✓ Providing opportunities for enhanced collaboration with MCBH-funded SIDS/ID Centers and cooperative agreements;
- ✓ Continuously exploring and evaluating opportunities for enhanced collaboration with other organizations like the March of Dimes.