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 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 effected 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 preliminary cause of death, preferably within 24-48 hours of death;
- To provide counseling for families bereaved by sudden and unexpected loss of the 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 to evaluate, improve, and better coordinate services provided by projects and peer support organizations.

Following the federal government’s consolidation of funding for MDH 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.

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.
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 other 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 government's withdrawal. The ASPP represented health and human services professionals who provided services to nearly 4000 families each year who experienced the death of a child due to SIDS. In 1996, 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 others may choose to use only selected standards according to the scope of their programs.

To view the full document: The Unexpected Death of an Infant or Child: Standards for Services to Families go to: http://www.asip1.org/images/ASIPStandards.pdf