PROJECT ABSTRACT

Project Title Family Support after an Infant Loss Home Visit Program

Organization Name Monroe County Health Department

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PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS: The Family Support After An Infant Loss Home Visit Program (The Family Support Program) seeks to reduce infant mortality by providing support and preventive services following the death of an infant. The program was developed in response to infant mortality review recommendations which addressed the lack of a universally available bereavement support/follow up program and a lack of consistent preventive health information that could potentially affect future birth outcomes and infant deaths. This program provides bereavement support/follow up and targeted educational interventions to address preconceptional health and other family issues that impact on the health and well being of mothers and children. The service is available to all women sustaining an infant death with emphasis on urban women who, as a subset of the general population, have had consistently high rates of negative health indicators. The goals of the program are consistent with those of the Maternal and Child Health Services (MCHIP) Block Grant Program (Title V, Social Security Act, as amended) which seeks to improve the health status of mothers and children by enhancing the operation of agencies or health care systems.

GOALS AND OBJECTIVES: This project identified a Health Systems goal and a Health Status goal. The Health Systems goal stated that families who experienced an infant death would have access to a comprehensive integrated system of information, counseling and support services

through development and implementation of a universally available loss and bereavement program. The Health Status goal stated that families would be at reduced risk for subsequent poor birth outcomes and infant mortality through public health nurse home visits to provide health information, education and case management services.

METHODOLOGY: A public health nurse (PHN) home visit bereavement support program was developed as a community service available to all families who sustain an infant loss. During home visitation, a PHN provided bereavement support and information about grief and grieving as it affected family members and facilitated utilization of community resources. Using the March of Dimes Preconceptional Health Promotion nursing module as a guide, the PHN offered preconceptional health assessment and education to all women expressing an interest in family planning and/or future pregnancies. Families demonstrating limited parenting skills or knowledge related to child growth and development and community resources received preventive education and linkage with services such as day care, early intervention programs and child specific bereavement programs.

EVALUATION: The evaluation plan for the Family Support Program was designed to measure process, outcome and cost variables assessing the program as a whole as well as the individual services offered. An essential part of the evaluation is documentation of utilization and participation rates as a whole and as individual components. Participant satisfaction with services provided is a process measure obtained through completion of an anonymous satisfaction survey sent to the mother upon discharge from the program. Upon completion of the demonstration project, an independent anthropological evaluator conducted interviews with a sample of participants.

RESULTS/OUTCOMES (POSITIVE/NEGATIVE): Two hundred four (204) women were identified as having sustained an infant death between July 1, 1995 and June 30,1998. One hundred five (105) women, representing fifty one percent (51%), consented to participate in the program. Eighty-eight (88), or forty three percent (43%), received two or more home visits. Bereavement support was provided to all participating women/families. Sixty nine percent (69%) of all

participating women accepted some information on preconceptional health and this percentage rose to seventy one percent (71%) for those accepting two (2) or more home visits. Family issues were addressed with sixty one percent (61%) of all participating women and again the number rose with women who accepted continuing service. Sixty percent (60%) of infant deaths were to women living in the city. Urban women comprised fifty seven percent (57%) of all women who consented to participate and fifty eight percent (58%) of women accepting two or more home visits. Urban women accepted preconceptional and family health education more often than did suburban women. Sixty five percent (65%) of satisfaction survey respondents felt that the bereavement service offered was meaningful to them and fifty seven percent (57%) stated that it helped them to cope with the loss of the baby. The most successful method to engage women in the program was the home visit, most often unannounced. The PHN was instrumental in assisting women who lost late term infants and very young babies to develop a support group with one to one peer contact. She also assisted in reorganization of the regional SIDS Parent Support Group. The plan to maintain contact with women who were not participating was not as successful as envisioned. Letters and telephone calls to women at three month intervals, to offer support and ascertain needs, produced few responses and those responding most often were women with whom the nurse had an established relationship. Issues around staffing and peer support for the PHN arose out of the dedication of only one staff person to the program and the lack of in-house or community peer support for the PHN. The rigidity for home visit frequency did not ensure successful ongoing intervention by participants.

PUBLICATIONS/PRODUCTS: A protocol, program brochure, and data collection system were developed for use with the program. Wherever possible, the nurse made use of existing educational and assessment tools.

DISSEMINATION/UTILIZATION OF RESULTS: Project staff have presented the program to: the NYSDOH Combined IMR and SIDS program Meeting in Albany, 1998; PHNs at the Seneca County Health Department, Waterloo, N.Y.; Monroe County DSS Child Abuse Networking Committee, Rochester, N.Y.; Healthy Start Rochester, N.Y. clients; Monroe County Health Department public

health nurses and paraprofessional outreach staff as part of standard orientation; day care workers in a local day care program; the Fourth and Fifth International SIDS Conferences, 1996 and 1998; the Third National NFIMR Conference in 1998; the First Annual Healthy Start Rochester Conference, 1998. In 1999, the CityMatCH Urban Leadership Conference highlighted FSP in their program profiles.

FUTURE PLANS/FOLLOW-UP: The Family Support Program has been integrated into the service array offered by the Maternal Child Health Division of the Monroe County Health Department. Flexibility has been built into protocols to better meet the needs of families and program parameters for service have been expanded. Other staff within the Maternal Child Health Division are receiving training to provide bereavement support to SIDS and other infant death parents, thus providing consistent staffing and peer support for the staff providing service. A core curriculum that includes basic knowledge on grief and bereavement support has been developed for all current Child and Family Health Service workers and will become part of the orientation process for new employees. This will ensure that all employees have the basic skill to provide support to bereaved families for whom they may be providing other services.

TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE: Replication of this program is possible. It is dependent upon the number of infant deaths occurring in the proposed site, the ongoing obligations of the parent agency and the availability of personnel and financial resources. For this project, the initial estimate for staffing was based upon an average of 100 deaths per year and a FTE nurse making 800 home visits per year with necessary coordination and documentation. Administrative, supervisory and clerical support must be included in program costs. Other costs include mileage reimbursement for the PHN, reference materials for the PHN, office supplies, rental of office space, utilities, equipment, mailing costs, and educational materials for clients. Initial one time costs such as equipment need to be considered. Peer support for the home visitor should be built into the program and a plan to address the peer support needs for the parents should be in place.

2. ANNOTATION:

The Family Support After An Infant Loss Program provides bereavement support and health education to women and families experiencing the death of an infant. The program was developed in response to Infant Mortality Review recommendations which addressed the lack of a universally available bereavement support program and a lack of consistent preventive health information that could potentially affect future birth outcomes and infant deaths. Identification of infant deaths is accomplished through receipt of infant death certificates from the Office of Vital Statistics and reports from the Medical Examiner's Office. A public health nurse approaches all bereaved mother/families to provide support and offer services. Through home visitation, the public health nurse is able to assist women to assess their health and social needs, providing education or facilitating referral to community resources when appropriate. Targeted interventions address interconceptional health and other family issues that impact on maternal well being and infant health.

3. KEY WORDS:

home visiting, public health nurses, bereavement support, infant mortality, preconceptional health education, family health education, SIDS support, other infant death, risk assessment, maternal child health, health departments.