Northeastern North Carolina Baby Love Plus Healthy Start Impact Report 2000 - 2003

North Carolina

Grant Number: H49 MC00037

Healthy Communities . . . Healthy Babies . . . Healthy Start

PURPOSE:

The purpose of the Healthy Start Baby Love Plus Initiative is to improve perinatal health disparities by reducing infant morbidity and mortality. This is being addressed by:

- Enhancing the effectiveness of existing Baby Love services and
- Introducing new interventions that complement these existing services.

INTERVENTIONS:

Local and Regional Consortium development to increase community and agency coordination and collaboration to build programs that reflect the needs and values of the community. Family involvement is critical to the success of the consortium and project.

Improved Access to Care by providing transportation (and at times, childcare, and interpreter services).

Outreach primarily to women of childbearing age to increase their access to and knowledge of available health and human services. The community health advocates are the bridge between the communities and agencies.

Enhanced Clinical Services to increase community satisfaction with services and agency capacity to deliver care.

Case Management to enhance efforts to better match a pregnant family's needs with the services provided.

Health Education and Training to improve awareness and knowledge of maternal and child health issues.

Community Planning Process in the belief that communities themselves can best develop the strategies necessary to address the causes of infant mortality.

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Healthy Start Impact Report
2000 – 2003

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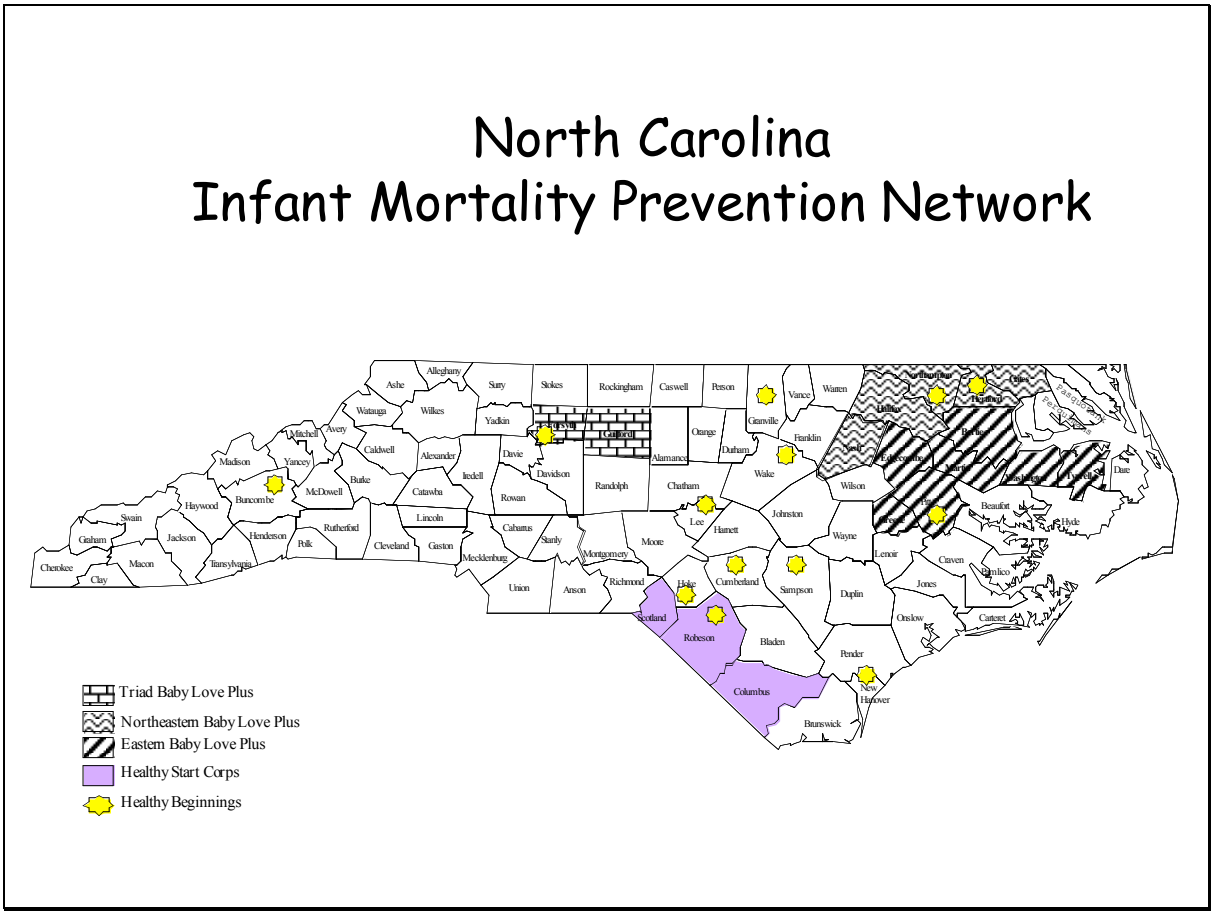
I. Overview of Racial and Ethnic Disparity Focused On By Project

Northeastern NC Baby Love Plus is an initiative focused on improving birth outcomes and perinatal health of African-American and American Indian women and their families living in Gates, Halifax, Hertford, Nash and Northampton Counties. In the northeastern area, as in North Carolina as a whole, there is a disproportionately high infant mortality rate among racial and ethnic minorities. The project strives to close the gap in racial disparities among African-Americans and American Indians and Whites in the project area. The priority population is African-American and American Indian women of childbearing age (15-44 years) and their families.

The five project counties have small populations, making up only 2.5% of the state's population. According to the 2000 census, the total population for the project area was 199,993; 50.9% of the population (101,886) is White, 45.3% (90,519) is African American, 1.2% (2,582) is American Indian, and 2.1% (4,114) is of Hispanic origin. There are 45,360 women of childbearing age (15 – 44 years) in the project area.



Poverty is a major problem in this area which is noted as a contributing factor to poor birth outcomes and perinatal health status. The U.S. Census Bureau (2000) reported that 11,510

children in the project area under 18 years of age lived in families with incomes below the federal poverty level ($14,150 for a family of three).

Educational attainment, a contributing factor to the depressed economic, health, and social indicators of the area is low. Concerns about low educational attainment are widespread among local community members. According to 2000 U.S. Census figures, 40% of women 25 and older had not obtained a high school diploma or equivalency degree. Among African-Americans females, the corresponding percentage was 39.3% and was 52.6% for American Indian females while the figure for White females was 19.7%.

Live Births

During the four-year period 2001 - 2004, 10, 609 live births were recorded in the project area. Of the total number of live births during this period, 43% (4,537) were to White females, 49% (5,234) to African-American females, 2% (182) to American Indian females, 5.4%(569) to Hispanic females and 0.8% (87) to Other females. Teens under the age of 17 years accounted for 5.3% (557) of total live births and 33% (351) of the teen births were to African- American females and 1% to American Indian (8).

Of the women in the project area who gave birth during 2001 – 2004, 81.4 %(8,633) entered prenatal care during the first trimester. African-American females (3937 or 37%) and American Indian women (159 or 1.5 %) begin prenatal care in the first trimester. African-American females (84 or 8.0%) are twice more likely to receive no prenatal care than White females (30 or 3.0%) statewide.

Adequacy of care for 2002-2004 for the region was examined using the Kotelchuck Index. Although the vast majority of females (74 %) received adequate or better than adequate, only 68% of African-American women received adequate or better care, while nearly 85% of American Indian women in the region received adequate or better care. During this period statewide 79% of all women received better than adequate or adequate care also 70.3% African American women, 75% American Indian women, 60.1% Hispanic and 82.2% White women received adequate prenatal care.

Infant Deaths

The project area has recorded some of the highest infant mortality and morbidity rates in the state. During 2001 - 2004 there were 120 infant deaths in the project area for a regional rate of 11.0 compared to the state rate of 8.9. In the region African-American infants accounted for 76% (91) of the deaths versus 17% (20) of White infant deaths. Statewide African American infants accounted for 44% of infant deaths (1760 of 3979) and American Indian infants accounted for 2% of infant deaths (69 of 3979).

Northeastern Region Infant Mortality Rate 2001-2004						
County	**Total**	**White**	**African American**	**American Indian**	**Other**	**Hispanic Origin**
Gates	11.0	8.0	14.1	0.0	0.0	0.0
Halifax	10.6	0.0	17.2	10.0	23.0	0.0
Hertford	22.9	24.6	22.5	0.0	*83.0	0.0
Nash	12.7	8.0	20.0	* 62.5	12.0	11.0
Northampton	13.8	7.3	17.2	0.0	0.0	0.0
Region Total	11.0	4.0	17.0	22.0	26.0	9.0
Total Number of Deaths	117	20	91	4	2	3
North Carolina	8.9	6.0	16.0	11.0	5.0	5.0
	*Rate based on only one infant death in the period, 2001-2004.					

While some improvements have been made over time, the infant death rate for the region continues to be above the state average.

Healthy mothers are more likely to have healthy babies .and planned pregnancies are likely to result in positive birth outcomes. Unintended pregnancies are more likely to result in health problems for the mother and child. During 2001-2003 for the region 59% of the project area births were unintended and 47% statewide. In the project area special outreach efforts were used to recruit and retain African-American and American Indian women in the perinatal system of care.

Premature and Low Birth weight Birth

While the majority of infants in the project area began life at an acceptable weight, far too many are born too early and weighing too little. During 2001 -2004, 939 babies were born weighing 2,500 grams or less in the project area. African-American babies accounted for 61% of this low birth weight (577) and 74% very low birth weight (200) babies. For American Indians, the rates were 3% (27) low birth weight 2.6 %(7) very low birth weight. Lifestyles and medical issues exacerbate slow gestational weight gain and premature delivery which points to the increased need to provide interventions to women during the interconceptional period.

Sudden Infant Death Syndrome (SIDS)

From 2001 – 2004 the Sudden Infant Death Syndrome (SIDS) rate for the project area was higher than the state rate (13.0 versus 8.15 deaths per 10,000 live births). There were 386 total SIDS deaths statewide during this period. Of the 12 SIDS deaths in the project area during this period, 7 were African-American and 1 American Indian death. The NC Pregnancy Risk Assessment Monitoring System (PRAMS) 2001-2003 data reveal that children are as likely to be put to bed on their sides (21.6) or on their backs (61.0) compared to their stomach (17.4).

Table 2 Sudden Infant Death Rates 2001-2004						
	Gates	**Halifax**	**Hertford**	**Nash**	**Northampton**	**North Carolina**
2001	0.0	13.1	0.0	8.0	0.0	8.6
2002	0.0	0.0	0.0	16.7	0.0	6.9
2003	0.0	0.0	17.0	17.0	0.0	8.5
2004	0.0	14.0	0.0	8.0	0.0	8.6
2001-2004	0.0	7.0	17.0	12.0	0.0	8.15

Physical Violence

According to NC Pregnancy Risk Assessment Monitoring System (PRAMS) mothers who reported physical violence in 2003 had a greater prevalence of delivering a low birth weight (<2500 grams) baby (10.3%) than those who did not report any physical violence (7.9%). Also during 2001-2003 PRAMS data reveal that 8.5 % of women reported physical violence before, during, or after pregnancy.

The project area has three family violence programs, which provide community education, advocacy and safe haven for those in crisis. WCHS partners with the programs, along with the health departments, in implementing the federal grant "Addressing Family Violence During and Around the Time of Pregnancy".

Summary

A detailed community needs assessment was conducted prior to project implementation. This initial needs assessment identified a wide range of factors which had an impact on birth outcomes in the African-American community. As noted above, these factors included poverty, low educational levels, health of mother, and delayed entry into prenatal care. A recurring theme in the project area was a sense of alienation from providers of health care and a sense that consumers were not respected by providers. Feelings of disenfranchisement and powerlessness were expressed. The project sought to focus heavily on the issue of alienation from the health care system among members of minority communities. In addressing this issue it was anticipated that access to the perinatal health system would increase, consumers would take a proactive stance towards health and wellness. Hence, by taking these actions birth outcomes would improve.

The objective of Northeastern Baby Love Plus was to achieve community-based infant mortality reduction through innovation in service delivery, community commitment to the plan, increased access to services and resources, and multi-agency participation to facilitate incorporation of related programs into the plan.

II. Project Implementation

A. Model Selection and Rationale

The goal of Northeastern NC Baby Love Plus Program is to prevent infant death and improve the health of African-American infants and their mothers living in Gates, Halifax, Hertford, Nash and Northampton Counties. As noted in the previous section, there have been some improvements in the regional infant death rate over time; yet, the rate for the region continues to be above the state average. Exacerbating the high infant mortality rate and overall poor health status of African-American and American Indian women were a mixture of system and client-imposed barriers. Annually, community input was sought to help identify community needs.

Case management was firmly entrenched in the project region, through NC's Baby Love Case Management Program, Maternity Care Coordination (MCC). This Medicaid service covers case management for pregnant women through 60 days postpartum. To fulfill Healthy Start Initiative requirements, the following enhancements were provided through Northeastern Baby Love Plus:

- The "Plus" included intensive outreach and client recruitment.
- The "Plus" allowed for women and their children to be followed for two years interconceptionally.
- The "Plus" included depression screening and referral.
- The "Plus" included health education and training to staff, other health and human service providers, and the community at large.
- The key "Plus" was the partnership between the Northeastern Baby Love Plus Regional Consortium and the NC Department of Health and Human Services, Division of Public Health, Women's and Children's Health Section (WCHS), the applicant agency. This partnership allowed for increased coordination of service delivery for families and providers throughout the region.

All of the required core services and system building efforts were included in this Healthy Start initiative. Northeastern NC Baby Love Plus developed several special initiatives as addressed in the table below.

Table 4
Program Response to Required Core Services & System Building Efforts

Core Services	Program Which Addressed Change	Core System-building Efforts	Program Which Addressed Change
1. Outreach and Client Recruitment	• Community Health Advocates (7) • Network Liaisons (2) • Public Awareness & Marketing	1. Local Health System Action Plan	• Development of Local Health System Action Plan • Bi-Monthly Regional Consortium Meetings • Facilitating Services - Transportation
2. Case Management	• Maternity Care Coordination • Facilitating Services - Transportation	2. Consortium	

2. Health Education and Training	• Public Awareness and Marketing • Healthy Start Training Institute	3. Collaboration and Coordination with State Title V	• Family Leadership Development • Community Sub-Contracts Program
3. Interconceptional Care	• Child Services Coordination Family Planning	4. Sustainability	
4. Depression Screening and Referral	• Edinburgh Depression Screening		

B. /C. Model Components and Resources

Case Management

During the funding period, project area health departments employed 9.5 FTE Maternity Care Coordinators (social work and nurse case managers), along with 6.0 FTE Maternal Outreach Workers (trained paraprofessionals) to staff their prenatal case management programs. Services are offered to all Medicaid eligible and some non-Medicaid eligible women. Maternity Care Coordinators (MCCs) provide assessment, service planning, coordination, referral, monitoring and education for pregnant and postpartum women. Each MCC carries an average caseload of 75 women over a calendar year. The Maternal Outreach Workers (MOWs) work under the care plan of the MCCs and carry a caseload of 25-30 clients at any given point in time. They provide outreach and support services through home visitation. Twin County Rural Health Center (Rural Health Group) also provided MCC and MOW services. They employ two MCCs and two MOWs.

Outreach and Client Recruitment

The Outreach and Client Recruitment intervention was designated by federal Healthy Start as a core requirement. However, the Northeastern Baby Love Plus (NEBLP) program operationalized this core requirement by building upon the state's Baby Love Program. A significant component of the Baby Love Program is the Maternal Outreach Worker (MOW) Project. Supported by Medicaid revenues, outreach workers are hired and trained to provide additional support to low-income pregnant women with multiple needs. Presently, all five of the counties (Gates, Halifax, Hertford, Nash, and Northampton) have MOWs or similar positions. Love Maternal Outreach Workers work one-on-one with women referred by the Maternal Care Coordinator. However, because they carry client caseloads, they have very limited client recruitment responsibilities, and for this reason population-based education and case finding within the communities is limited. The level of internal responsibilities for the MOWs, along with the primary results of community surveys helped Northeastern NC Baby Love Plus staff understand the need for a program component that would more intensely inform, educate, recruit, and follow-up with women regarding perinatal health care and program services. Subsequently, Community Health Advocates (CHAs) were added to enhance the continuity of care, recruit women in to early and continuous care, and provide information, education, and referrals to and for pregnant women and women of child-bearing age. The CHAs have proven to be an integral

part of the Baby Love Plus program by decreasing the gaps in the system through referrals and follow up.

A core outreach activity of the Northeastern NC Baby Love Plus has been the recruitment and referral of African American and American Indian women of childbearing age (15-44). Community needs assessments, surveys, focus groups, and input from Regional Consortium members has been extremely important in identifying the needs of these women. The results of this comprehensive information-gathering process indicated that the program needed to: 1) identify women who needed prenatal care earlier as a better way to improve birth outcomes; 2) develop a public information campaign to raise community awareness; and 3) increase participation of community members in perinatal health service efforts. Information from this fact-finding process also revealed that outreach efforts conducted by individuals who were residents in the five participating counties would be more effective. This particular strategy was implemented in order to 1) facilitate a trusting relationship with the communities, and 2) assist in an accelerated identification of natural leaders in the community who could then lead the Community Health Advocate (CHA) to women who needed Northeastern NC Baby Love Plus services. Subsequently, persons hired for the Maternal Outreach Worker (MOW) and the Community Health Advocate (CHA) positions were members of the populations served. The interactive relationship between the MOW and CHA has contributed greatly to the success of Northeastern NC Baby Love Plus outreach and client recruitment efforts.

Seven (7) CHAs serve the five-county project area. The number of CHAs assigned to the counties within the region varies according to the county's population size. The two largest counties, Halifax and Nash, each have two CHAs, whereas the smaller counties, Gates, Hertford and Northampton each have one. Their focus was to recruit African American and American Indian pregnant women and women of childbearing age. Ongoing training to CHAs was provided in order to enhance services to clients, as well as provide professional and economic development opportunities for the CHAs, the community and its members.

The program's empowerment and capacity-building process not only had an impact on program and community participants, but it also had an affect on employees. This impact was the source of the most significant change experienced by Northeastern NC Baby Love Plus between 2000 and 2003. During this time period, Northeastern NC Baby Love Plus lost three CHAs who became full-time college students. Two received degrees in Social Work, and one received a degree in Nursing. Upon receiving their degrees, the CHAs sought employment opportunities within the public health field, specifically involving women's health. Things learned and skills received in helping program participants prompted several CHAs, during the time period mentioned above, to seek higher education. However, while these individuals left the program, those who remained took on other more responsible Northeastern NC Baby Love Plus positions, and/or elected to work with other programs that directly collaborated with the Northeastern Baby Love Plus program. While this event was a challenge for the program, Northeastern NC Baby Love Plus continued to provide comprehensive outreach services to program participants.

As a means to enhance the efforts for client recruitment, a region wide public awareness campaign was conducted. Printed materials, radio and television public service announcements and other media markets were used to increase awareness of resources and program activities.

This campaign worked in tandem with the existing Eastern Baby Love Plus Program in that many of the media markets were similar. Consumer input was used to design a "consumer friendly" outreach intervention.

The addition and subsequent integration of the Community Health Advocate both facilitated and detracted from the implementation of Northeastern NC Baby Love Plus's outreach efforts. Although the addition of the CHA permitted the program to recruit/identify women earlier, as well as maintain their participation in the program, the integration of the CHA into their work environments at the health departments was initially a great detraction. During the initial project stages the CHAs were not a part of the local health departments' case management team. They were affiliated with the Health Education section and supervised by the Health Education supervisor. This was identified as a barrier in the early stages of the program, and the decision was made to incorporate them into the case management/maternity care coordination teams at the local health departments. Working with this team, the CHAs followed up on missed appointments to determine the reason for the missed appointments and assisted program participants in reducing barriers to service provision. The move to these teams has proven to be extremely successful. CHAs are now able to participate in regular meetings with case managers, be supervised by the same local supervisor without having additional cost to the project, and provide more intensive follow-up on the high-risk and hard to reach clients. This transition has provided a cohesive team for the agency and has improved outreach and recruitment services to the clients. Providing clarification to the local health departments as to the different role/responsibility of the CHA, in comparison to that of the MOW, also contributed to the resolution this issue. (The CHA actively interacts with the community outside of the health department and recruits clients to access services, whereas, the MOW works one-on-one with clients "in house" that are referred to her via the MCC. The CHA does not carry a caseload which eliminates any overlap of roles with the MOW.

Health Education and Training

The Health Education and Training component is a Healthy Start requirement; however, Northeastern NC Baby Love Plus spent tremendous time and effort in identifying and addressing the local health education needs of participating counties. A cross-section of information gathering tools including surveys, focus groups interviews, community needs assessments, and key informant interviews assisted Northeastern NC Baby Love Plus program staff and Regional Consortium members identify and prioritize needs. Subsequently, a comprehensive, multi-faceted, multi-level health education and training component was implemented that addressed the needs of program and community participants, Regional Consortium members, and program staff.

The rationale for the design and implementation of the health education and training activities is found in the program's premise that " . . . communities, given the resources and opportunity can best design and implement the services needed by the families in that community." In addition to promoting the adoption of healthy behaviors in program participants, the health education and training component aims at: 1) improving advocacy skills of consumers and their families; 2) improving agency receptiveness to working with the community; and 3) increasing community ownership of the overall Northeastern Baby Love Plus Program.

Training was provided on three different levels which included provider, consumer/community member and staff trainings. In addition to coordinating specialized trainings for the three separate groups, the program also featured the Family Leadership Development Retreat and the Healthy Start Training Institute, a statewide collaboration that brings members of NC Baby Love Plus programs together.

During the Family Leadership Development Retreats, participants have the opportunity to learn and practice skill-building around personal and community advocacy and empowerment issues. (It is a more intimate training environment for program participants and their families.) More than one hundred families participated in the annual retreat during the initial four years. Several training topics were covered including financial management, stress and anger management, nutrition and effective family communication. The Healthy Start Training Institute is a two-to-three day conference in which program participants, the general community, and providers have the opportunity to learn about issues related to women's and children's health, and to dialogue about community development issues. Consumers and community members are integral to the planning for the Family Leadership Development Retreats and the annual Healthy Start Training Institute. (The Family Leadership Development Retreat is a feeder for the Healthy Start Training Institute.)

Provider trainings were conducted based on annual assessments to determine what types of trainings were needed and or desired. The trainings included issues related to domestic violence, substance abuse and perinatal depression. A consumer survey found that many clients had negative concerns related to the quality of customer service given by providers in the region. They also noted that at several health care facilities they visited, the staff was not racially diverse. To address these concerns, providers received trainings on customer service and cultural diversity. These two particular trainings were identified as a priority for providers in the northeast and are given at some level on an annual basis.

Northeastern Baby Love Plus staff trainings were offered bi-monthly, (especially for the Maternity Care Coordination team) and were designed to enhance outreach efforts, particularly by strategizing plans of actions for each county. Each meeting held a case analysis that reviewed the pros and cons of a particular encounter between a Community Health Advocate and a consumer. Additional training for the Community Health Advocates and Network Liaisons to enhance their outreach efforts was built into their regular team coordinated by the Regional Manager. At the January 2001 team meeting, outreach training was conducted. Staff trainings were generally centered around psychosocial issues such as domestic violence and substance abuse. Trainings were repeated as new staff came on board.

In addition to the aforementioned levels of trainings, providers and staff were also sponsored to participate in statewide trainings with Baby Love, Adolescent Parenting and Prevention, and Men Are Nurturers Too! Also, all members of the regional consortium received educational sessions based on feedback from the participants from at least 50% of the meetings. The topics of greatest interest among consortium members during this project period included the following: Credit Counseling and Repair, Key Parenting Techniques, Personal Safety Tips, Obesity, Diabetes, and Financial Growth & Employment.

Staff continuing education updates/training will focus on the issues of cultural diversity and customer service training. These issues were identified as concerns by local staff and in perinatal health forums. Using the customer service training initiative of the Eastern Baby Love Plus Program, at least one customer service workshop was held annually for health and human service providers in project counties.

Knowing that health education messages do not reach all individuals at the same rate, a multi-dimensional approach to the dissemination of health education messages was presented. There were multiple levels of training aimed at reaching Regional Consortium members, health care providers and the general population. The regional manager was primarily responsible for coordinating and implementing the various trainings. However, because of the magnitude and complexity of the different levels of trainings, the Regional Consortium committees and adhoc committees assisted in the designing of trainings. Consumer input was relied upon in developing all trainings related to community development and social interactions. In addition, consumer input was used in designing all printed materials, radio and television public service announcements, and other media markets.

The evaluation team provided feedback on the multiple levels of health education and training activities using several data collection strategies. Results were summarized within one month of receiving data summaries, and presented on a regular basis to the respective groups (Consortium or management team) to enable them sufficient time to incorporate suggestions and findings into subsequent training activities. Both areas that were successful and areas that required attention were identified in this process. The presentation of these results also assisted the program in achieving its goal of continuous quality improvement in trainings offered through Northeastern Baby Love Plus.

Information was also provided during the contacts made by the CHAs. CHAs provided one-on-one education and support within their local communities. They held house parties and other group sessions. The CHAs completed monthly tracking forms to record both individual and group contacts.

The partnerships, contacts and networks developed by the Regional Manager from previous employment, along with being a native of the area were very instrumental in facilitating the successful implementation of the NEBLP health education and training activities, particularly those that were consumer/community focused.

A significant detracting event during this time period was the lack of response from the American Indian community. Initially, American Indian representation on the Regional Consortium did not reflect this population's presence in the region. However, because program staff knew of the importance of the American Indian input in the design and planning of interventions, efforts were made to ensure that their concerns were heard, and incorporated into the implementation of the health education and training component. NC Baby Love Plus teamed with Healthy Beginnings (the state's minority infant mortality prevention program), NC Health Choice (CHIP), and the NC Healthy Start Foundation to work on a collaborative venture to reach the American Indian population in each program's service delivery area. Early in the project

period, several meetings were convened to discuss the issues. The focus was on building program partnership to reduce infant mortality disparity.

The Regional Manager continued the dialogue with tribal leaders in both the Meherrin (Hertford County) and Haliwa-Saponi (Halifax County) tribes to discuss their health, environmental and social concerns. After members of the Tribal Council prioritized their concerns, the Regional Manager offered support and resources from the Northeastern Baby Love Plus Program to sponsor any community forums or events they deemed necessary. In an effort to build a more effective partnership with this population, the Regional Manager serves on the Native American Public Awareness Committee. This entity is composed of members of the state's various American Indian tribes and other public health leaders. This approach in meeting the health education needs of the American Indian population has promoted a partnership with NEBLP that was based on trust, respect, and commitment.

Interconceptional Care

Interconceptional care was not a part of the Healthy Start repertoire during the 2000 – 2003 project period. However, program participants and their infants were followed interconceptionally through Child Health Clinics, Child Services Coordination or Family Planning programs. Interconceptional care as a program model (with staff) was added to Northeastern NC Baby Love Plus in the 2004 – 2008 grant cycle.

The marjority of infants were followed through traditional Child Health Clinics. Children were seen for regular scheduled visits based on American Academy of Pediatrics guidelines. Nursing, medical, social work, and nutrition staff provided routine screenings and health guidance. Routine screenings offered include assessment of vision, speech, hearing; physical and developmental screening; screening for anemia and lead poisoning and various chronic diseases; nutritional screening; and dietary counseling services.

Children with special health care needs were followed through the Child Services Coordination Program. This program includes specially trained nurses and social workers who work with other health and social service providers to monitor children's development, strengthen parent-child interactions, foster family self-sufficiency, provide information about available programs and services, and help to locate appropriate resources. Children from birth to age five who have certain parental/family, neonatal, post-neonatal or diagnosis are eligible. There is no income eligibility criterion for the CSC Program.

Depression Screening and Referral

Depression screening and referral was not an original grant component. Limited screening was conducted as part of the basic maternal health program. In the early funding period, there was no specific tracking procedure used by the local providers to follow up on mental health referrals. When depression screening and referral became program requirements, this component was added to the case management program. The emphasis was on system analysis, provider education, and developing a referral tracking system. The local health department staff received

training on Perinatal Anxiety and Mood Disorders on January 31, 2003 and began using the Edinburgh Postnatal Depression Screening Scale in February 2003.

Thereafter, depression screening was provided as a standard part of case management. Program participants enrolled in the case management and interconceptional care components of the program were screened for perinatal depression during pregnancy and during the postpartum period. The MCCs became responsible for screening clients for depression and for coordinating assessment, referral, treatment, and follow-up services. Considerable time has been spent developing relationships with mental health providers to ensure that women who screen positive have access to appropriate mental health services.

Local Health System Action Plan

The primary purpose for the development of the Local Health System Action Plan (LHSAP) was to lay out a strategy that 1) integrated various components of the perinatal service delivery system so that the project communities would be better served; and 2) assure the provision of quality services to meet the social, emotional, and medical needs of parenting women and their families in the priority communities. This holistic approach respects the dignity of the individual and her family, treating each woman as a person with specific strengths as well as needs. With this aim in mind, the LHSAP provided a framework for developing collaborative relationships in order to model solutions to local conditions underlying disparities in the high rate of poor birth outcomes in the northeastern project region. The LHSAP goals of changing patterns of behavior and responses to adverse living conditions are broad. The challenges faced by many in the region are pervasive. The anticipated intent of the LHSAP is to improve living conditions in the region and the ability of community members to manage their lives more skillfully. Health and social welfare services are limited in the region in part because it is both rural and poor. The organizations that serve communities in the region will have greater impact when they collaborate so that each organization is able to maximize its strengths and not duplicate efforts in the same area.

The LHSAP was developed through the Regional Consortium and its County Action Committee with technical assistance from the *BLP* evaluation partners at UNC Sheps Center. To identify priorities in the LHSAP, the County Action Committee met regularly with the Regional Manager, the Chair of the Consortium, and the *BLP* evaluation team. Considerable time was spent in collecting, compiling, and reviewing all significant data that had been compiled for the project area. This included community diagnoses, need assessments, surveys, Northeastern Baby Love Plus project data as well as regional and state infant mortality and morbidity data, and a regional Perinatal Periods of Risk Assessment.

Input into the LHSAP was received from general Regional Consortium members, program outreach and case management staff, and interviews with local and state partners. Two focus areas were identified after a series of study and discussion sessions. One area focuses on the need for supportive housing, security, and a healthy living environment, while the second area focuses on developing effective coping skills, positive interpersonal relationships, and resiliency in family life. Goals, rationale, target audience(s), local partners, and initial action steps for each area were identified, and a plan was submitted to the Regional Consortium and adopted by vote of the Consortium.

The Committee also decided that partnering with a local Community Development Corporation was a natural collaboration, and that the LHSAP would benefit from the grant-seeking expertise of this non-profit Corporation. The corporation is developing a program to address unstable housing and provide training in skills necessary to prepare people for home ownership. The Committee decided to collaborate with the Corporation on this project. The rationale for this decision came in part from lessons learned during a three-year project titled "Assessing Family Violence During and Around the Time of Pregnancy" in the region that concluded at mid-year. The Committee saw that lack of housing security has a reciprocal relationship with risk for family violence, for poor birth outcomes and poor crisis management skills. This collaboration has been and continues to be a great asset to the LHSAP process.

The major challenge faced in developing and implementing the plan has been in maintaining the initial start-up momentum and enthusiasm of the volunteer action plan workgroup. In implementing the LHSAP the usual challenges of working in a worsening economy were faced. The project weathered some of the challenges by providing the technical assistance and infrastructure support to keep the work of the LHSAP moving forward. In the northeastern region of North Carolina, there is a limited availability of health care providers and institutions. In the absence of many institutional resources to support the efforts of the LHSAP, the Consortium calls upon the five health departments, local shelters and the *BLP*'s own Ministry of Health to assist with program activities. Despite these limitations, an active, committed group of providers, consumers and county leaders have come forward to work on developing the plan.

Consortium

As a core requirement for the Northeastern Baby Love Plus program, the Regional Consortium was created as a means to support and empower communities in the five-county region as they addressed local and state perinatal health issues. The Consortium was formed based upon the belief that a community guided by a group consisting of consumers, community members and agency representatives, could best design and implement the services needed by families in the community. Subsequently, Consortium activities were designed to 1) increase community and institutional coordination and collaboration regarding infant mortality reduction; 2) increase the percentage of consumers as active members on the Consortium; 3) to increase the community's investment and ownership in infant mortality reduction efforts; and 4) increase the knowledge and skills of consortium members through training and other skill-building opportunities.

Given the Consortium's charge to operate on behalf of the community, provide guidance and advise the NEBLP regarding all of its program planning, operations, monitoring, and evaluation efforts, a comprehensive needs assessment was carried out in the project area. Community feedback from this process, received from town meetings, focus groups, and community interviews cited poor nutrition as one of the primary causes of infant death. Additional data also supported poor nutrition is a significant problem, showing project counties to have a disproportionately high percentage of women who gained less than 15 pounds during their pregnancies. The overall challenge for the Northeastern Baby Love Plus Program was not only to provide and coordinate perinatal health services, but to mobilize communities within the five-county region, to take ownership (via the Consortium) of the infant mortality and morbidity

problem and take the leadership in implementing programs that will be successful in their communities.

However, during the initial stages of developing a plan of action to address poor nutrition in the region, Hurricanes Floyd and Irene hit, respectively, in September and October of 1999. Now many "one car families" were without any transportation whatsoever, living in communities that were struggling to survive. This natural disaster highlighted even moreso the inadequacies and need for transportion in the region. Due to the geographical isolation from social support systems, the key contributions from the Regional Consortium was how to maximize the available resources to best serve communities that were severely restricted. This ongoing assessment aided the Consortium in the development and implementation of services and activities to address this need.

Given that the consortium is a community-driven, community-focused entity, it was important that the organizational structure (components) and the decision-making process reflect this intent. Leadership for the work of the Consortium was provided by 1) a chairperson; 2) a vice chairperson; 3) an executive committee; and 4) three standing committees, (1) the Needs Assessment Committee; (2) the Public Relations Committee; and (3) the Consortium Formulation Committee. The Needs Assessment Committee worked with the Project Director and Public Health Consultant to conduct the comprehensive needs assessment. The Public Relations Committee was responsible for marketing the program, specifically at town meetings and regional consortium meetings. (This committee worked closely with outreach workers.) The Consortium Formulation Committee developed the guidelines for the formulation of the Regional Consortium. This included determining the Regional Consortium make-up, recommending a chairperson, determining the frequency and location of meetings and the initial work on the by-laws and procedures. A regional manager was hired to provide overall support to the Regional Consortium and assure that essential components of the consortium were developed and maintained. Network Liaisons were hired to cover the five-county region to provide support to the local coalitions. (These coalitions provided guidance for county-specific activities.) The Network Liaisons served as ombudsmen in the community to receive input and feedback from consumers and implement changes in service delivery systems.

The environment, agriculture, and economic stability of the 5-project area have been severely affected by an unusually severe hurricane season that took place between 1999 and 2004. During this time frame, three of five major hurricanes---Dennis, Floyd, and Isabel---severely flooded the project area. Hurricane Floyd produced the worst flooding in the history of the state. With each of the hurricanes, all project counties were declared federal disaster area(s). The overwhelming damages from the hurricanes greatly impacted an already exacerbated economic climate in the region. The health impact of these storms is still being accessed and the true long term impact is unknown. These storms occurred during the initiation efforts of the Regional Consortium. While initially it shifted the focus of the Consortium to addressing the immediate needs of the community (detraction), in the long-run these natural disasters mobilized the Consortium to function more effectively as a community capacity-building entity (facilitation).

Collaboration and Coordination with State Title V

The Women's and Children's Health Section (WCHS) is the state Title V agency and the grantee organization. The relationship that existed between WCHS and Northeastern NC Baby Love Plus Regional Consortium over the life of the project provided a partnership that promoted successful implementation of the project. Collaboration and coordination of effort helped insure that Northeastern NC Baby Love Plus was attuned to the specific needs of the project area and consistent with the State's vision for comprehensive community-based systems of service. As a component of WCHS, Northeastern NC Baby Love Plus was able to build upon a strong network of providers and partners in the project area and throughout the state.

WCHS networks and maintains collaborative linkages with a wide range of state and local service providers and resource systems in the planning and implementation of perinatal health initiatives in the state. Partnerships with other agencies and local non-profit organizations continued to permit WCHS to expand its perinatal health service delivery, referral, and educational resource capacity.

WCHS has developed and maintained a very strong relationship with the University of North Carolina (UNC) School of Public Health through its partnership with the Cecil G. Sheps Center for Health Services Research. Dr. Julia DeClerque, who leads the evaluation team that assesses Norteastern Baby Love Plus program efforts, is on staff at the Sheps Center. Dr. DeClerque is also responsible for the evaluation of the overall North Carolina Baby Love Plus Program. This partnership is a good example of the mutually beneficial relationship that exists between the WCHS and UNC-Chapel Hill.

WCHS also has a strong, long-standing relationship with the State's Office of Minority Health and Health Disparities (OMHHD). Since 1994, OMHHD and WCHS have jointly administered Healthy Beginnings, the state's minority infant mortality reduction program. This intervention has the same core goal as this Healthy Start initiative---eliminating disparities in perinatal health.

In addition to its partnerships with the health departments, community health centers, and hospitals in the northeastern region, WCHS worked collaboratively with churches and community-based organizations (CBOs). The goal was to work with agencies and organizations that were closely linked with the community and the priority population. On-going technical assistance and skill-building opportunities were provided to the organizations in order to enhance their program planning, implementation, monitoring, and evaluation capacities. This type of support increases self-sufficiency and enhances the capacity of these entities to function as a resource to their communities.

Likewise, Northeastern NC Baby Love Plus operated a request for application program for community-based organizations to implement innovative programs that complemented existing program services. Requests for Applications were issued in 2000 and 2001. Four programs were funded in 2000 ($83,119 total awards) and five programs in 2001 ($62,834 total awards) to provide family support, fatherhood initiatives, teen pregnancy prevention, and general skill development for young families.

Sustainability

Northeastern NC Baby Love Plus, led by the grantee agency, Women's and Children's Health Section (WCHS) consistently held that the most viable sustainability strategy for large scale Healthy Start interventions was to incorporate models which demonstrated to be successful into the state Medicaid program, and to allow the interventions to be supported on an ongoing basis by Medicaid reimbursement. It was a strategy that had a good track record in North Carolina in the past. WCHS staff worked in close collaboration with the state Medicaid agency, the Division of Medical Assistance (DMA). DMA agreed, early in the original planning process, to consider this initiative to be a comprehensive birth outcomes improvement demonstration project, one which, if shown to be both effective and cost-effective, would move from grant funding to Medicaid reimbursement. In addition, these services would become available to Medicaid recipients statewide. Dialogue was held with DMA throughout the funding period. Because of state budget shortfalls during the funding period, Medicaid was not in a position to add new programs.

A plus for Northeastern NC Baby Love Plus was the influence that the program has had on community empowerment and ownership. Members of the Regional Consortium truly embraced the program. When funding status was tenuous for Triad and Eastern NC Baby Love Plus, Regional Consortium members took it upon themselves to begin advocating for the funding. They began a series of calls and faxes to their federal representatives. Many of these consumers and community members who took up the cause had never before made such a move. This, we strongly believe, was the move towards community ownership of the program. It also speaks towards the community feeling that they had the power to evoke change. Community ownership is a major step in program sustainability.

D. Consortium

1. Consortium Establishment

The NEBLP Regional Consortium was formed as an outgrowth of the existing Hertford County Quality of Life Association's Minority Infant Mortality Reduction Project (MIMRP) Advisory Board. This organization, along with its board, had strong inroads into the five-county region for a number of years. Both the NEBLP and the Advisory Board believed adding new partners (membership grew to include strong representation from consumers, health and human service providers---both public and private---and other community leaders/organizations, i.e., NAACP), would expand and enhance local efforts to address infant mortality. The Regional Consortium that developed out of this partnership has representation from all five counties. The Consortium's primary charge was to provide guidance to NEBLP, and serve in an advisory capacity to address issues related to program planning, operations, monitoring, and evaluation. Consortium members were included in many aspects of the program, including the hiring of staff and the awarding of subcontracts to vendors for the implementation of program activities.

The Consortium's first regional meeting was held October 28, 1999, with subsequent meetings taking place on November 18th and December 20th of the same year. Forty to 50 individuals attended these meetings, with consumers making up approximately 35-40% of this attendance. The work of the Regional Consortium was primarily accomplished by three committees: 1) the Needs Assessment Committee; 2) the Public Relations Committee; and 3) the Consortium

Formulation Committee. The Needs Assessment Committee worked with the Project Director and a contracted Public Health Consultant to conduct the comprehensive needs assessment. During the January 2000 meeting, the complete needs assessment was presented to the full Consortium for final approval. The project plan was approved by the Regional Consortium during the February 2000 meeting. The final budget was approved by the Consortium chairperson, who, as a community member represented a local community-based organization that focused on fatherhood/male involvement efforts issues. The Public Relations Committee was responsible for marketing the program, specifically the town meetings and Regional Consortium meetings. This committee worked closely with the nine outreach workers to inform community and program participants of NEBLP program efforts. The Consortium Formulation Committee developed the guidelines for the structure of the Regional Consortium. This included determining the Regional Consortium make-up, recommending a chairperson, determining the frequency and location of meetings, and initial work on the by-laws and procedures. The full Consortium voted on all committee reports.

A Regional Manager was hired to provide overall support to the Regional Consortium and insure that essential components of the Consortium were developed and maintained. Staffing committees along with planning, conducting, and coordinating education and training activities enhanced the Regional Manager's opportunities for participation in the Consortium. Cultural diversity/awareness and customer satisfaction were primary areas where training was received. Curriculum(s) have been developed and trainings were conducted in conjunction with the North Carolina Office of Minority Health. They include general cultural diversity training and training focused specifically on working with African American families.

Local coalitions were formed at the county-level. These coalitions provided guidance for county-specific activities. Two Network Liaisons were hired to cover the five-county region to provide support to the local coalitions. Nash and Halifax counties shared one Network Liaison, while Gates, Hertford, and Northampton counties shared the second Network Liaison. These Network Liaisons served as ombudsmen in the community to receive input and feedback from consumers and implement changes in service delivery systems. The Network Liaisons also worked with the Regional Manager to coordinate local and regional infant mortality prevention activities.

During the initial stages the Regional Consortium decided to continue to hold monthly meetings. However, over time, the group voted to have bi-monthly meetings. This logistical move allowed committees time to meet during the month(s) in between the larger-body forum.

Three primary barriers emerged during the development and implementation of the Consortium:

Barrier #1: The first barrier encountered during this process was the concerns of consumers who expressed alienation and disrespect from perinatal health and other health care providers in the region: Consumers felt disenfranchised and powerless when receiving services. In designing the framework for a Regional Consortium, it was emphasized that the consumers would be the guiding force in the development and implementation of services. Such a consumer-driven focus has ensured that the needs of the families in the region were met by NEBLP, and has in many ways

buffered this alienation and disrespect.

Barrier #2: The second barrier that surfaced was the need for child care. Mothers with young children expressed a great need for this service in order for them to participate in the program. Securing the services of a certified child care provider, who was retained on an as-needed basis, has reduced child care as a barrier.

Barrier #3: Although all meetings were held at a central location, the ruralness of the region made transportation the third primary barrier addressed in 2000-2003. Local CBOs and churches were recruited to provide transportation. Locating and utilizing this community resource promoted consistent participation by program and community participants in Consortium activities.

2. Consortium Structure

The organizational (working) structure of the Regional Consortium consisted of a chairperson, a vice chairperson, and three standing committees: The Needs Assessment Committee worked with the Project Director and the Public Health Consultant to conduct the comprehensive needs assessment. The Public Relations Committee was responsible for marketing the NEBLP, specifically the town and regional consortium meetings. It also worked closely with nine outreach workers to market the program and establish collaborative efforts with local agencies. The Formulation Committee developed the guidelines for the formulation of the regional consortium. This included determining consortium make-up, by-laws and procedures, and meeting locations. An executive committee also guided the Consortium in accordance with the grant deliverables.

A regional manager was hired in January 2001 to provide overall support to the Regional Consortium and assure that essential components of the community-based consortium was developed and maintained. The regional manager also was responsible for coordinating opportunities for trainings and educational sessions to assist with organizational growth and advocacy skills. Total membership between 2000-2003 was 155, of which 106 individuals (68.4%) were active. There were 58 consumers of which 23 (39.7%) were active participants. The racial/ethnic composition was 81.0% African American, 9.6% White, 7.7% American Indian, and .8% other races.

Table
Regional Consortium Membership Status

	Percentage	Number
Public Agencies/Organizations	23.7%	36
Community-based Organizations	1.7%	3
Private Agencies/ Organizations	1.7%	3
Contracts w/ Healthy Start	12.7%	20
Other Providers	3.4%	5
Consumers	43.4%	67
Others, i.e., fathers and other males	13.4%	21

3. Consortium Assessment and Partnership

The Consortium is the fundamental base for securing community ownership of the issue of infant mortality. Because it represents and speaks for consumers in the five-county region, it is critical that the Consortium identifies, understands, and addresses the needs of the priority populations served. During 2000-2003, the Consortium conducted the following activities to assess ongoing needs, identify resources, establish priorities for allocation of resources, and monitor implementation.

a. Community assessments. Two were completed during the 2000-2003. The first assessment included questions on awareness and effectiveness of the local consortium and personal concerns related to the problem of infant mortality and the functioning of the local health care system. The second assessment measured the knowledge and skills of all consortium members, and was used as a tool to best design programs/ events that would be beneficial to the members based on their feedback.

b. Survey results. After each educational session and or community event, evaluations were given to participants. These assessments helped NEBLP identify improvements that needed to be made, also made staff aware of suggestions for planning. Approximately 20 different surveys were given in regards to specific events during the 2000-2003 time frame.

c. Planning meetings/retreats. The annual Family Leadership Development Retreat, the Healthy Start Training Institute, the Building Bridges Conference, and the Baby Love Conference have been the primary community-focused health education and training events implemented during 2000-2003.

d. Work of Regional Consortium committees (3), local coalitions, etc. The Needs Assessment, Public Relations, and Consortium Formulation were the three committees that carried out the work of the Regional Consortium. The Needs Assessment Committee worked with the Project Director and Public Health Consultant to conduct the comprehensive needs assessment. There was an executive committee that guided the Consortium in accordance with the grant deliverables.

e. Local Health System Action Plan. As a component of the NEBLP program, this action plan was a key tool in reaching the goals of the overall program. The contracted evaluation team conducted an in-depth analysis of the project area vital records using a modification of the Perinatal Periods of Risk Model (PPOR). This served as a tool to finalize planning decisions about where resources were most needed to improve morbidity and mortality for area mothers and infants.

f. Health education and training sessions- Ongoing trainings were offered on three different levels; staff, provider and community level. (See Health Education and Training Section)

g. Partnership between NEBLP and the Tribal Association. Collaborative efforts

between the Haliwa Saponi and Meherrin Tribal Associations, and NEBLP have developed into a very productive state/community partnership. The time taken to build trust and mutual respect has been rewarded with the Northeastern Baby Love Plus program's co-sponsorship of several Tribal events that are held in high esteem within that community, most notably the annual Pow-Wows.

h. Evaluation results – Results showed that there needed to be more cultural diversity training for staff in health care facilities in the northeast. Also, improved customer service skills for providers were noted as key concerns amongst consumers. NEBLP partnered with the NC Office of Minority Health and Health Disparities to conduct cultural diversity training. The Customer Service Training was done in collaboration with the Eastern Area Health Education Center.

The Northeastern Baby Love Plus program attempted to maximize available resources by collaborating with Hertford QUOLA, a local CBO that also targeted infant mortality. Local coalitions were formed to provide guidance for county-specific activities. Within the American Indian community, the Regional Consortium worked hard at building a trusting relationship with the local Tribal Association. As a result of these efforts, and infant mortality being a perinatal health issue for African-Americans and American Indians, a meeting between Tribal Officials and Northeastern Baby Love Plus program staff took place. An itinerary of actions, services and events to be implemented was developed.

4. Community Strengths and Collaboration

Three major strengths surfaced during NEBLP 2000-2003 activities. The first major strength noted is that natural leaders in the community emerged as strong community advocates. Residents no longer wanted to be left out simply because they lived in a rural area, were underserved and/or underprivileged. Many key leaders were now able to advocate for a better quality of life in their communities. Another major strength of the consortium development was in the marketing of the Regional Consortium as a vehicle for consumers, community members, and agency representatives to take ownership in designing and implementing services that were wanted and needed in their communities. The Consortium logically filled the need for an organization to receive community feedback and respond with community-oriented action plans. The Consortium was intended as the force that advised the program activities and provided leadership on key decisions for the communities that had a stake in the programs success

5. Weakness and/or Barriers Faced

Two primary barriers had to be overcome in order to ensure a fluid development of the Regional Consortium. First, consumers had to come on board to provide the crucial feedback based on their experiences within the health care system. However, a recurring theme in the project area was a sense of alienation from providers of healthcare and a sense that consumers are not respected or valued by providers. The second barrier was the ability to increase the awareness of infant mortality among members of the American Indian community. The American Indian community was not trustful towards agencies outside of their immediate environment, partially due to broken promises from other organizations that did not follow through with providing needed services in the community. This particular barrier was addressed by securing

representation of the American Indian population on the Regional Consortium, and on local community coalitions. Most notably, having an American Indian as vice chairperson for the Consortium was the first step towards establishing a trustful linkage with the Tribal association.

6. Increasing Community and Consumer Participation

NEBLP employed the following strategies in order to increase resident/consumer participation.

a. Provided attendance reimbursement for those who consistently attended Consortium meetings and were deemed dedicated consumers.
b. Provided on-site childcare at meetings. (The consortium meetings began as monthly noon day meetings but changed to early evening meetings to accommodate the majority of participants.)
c. Provided door prizes and other interactive activities after the meetings were adjourned to build camaraderie and team spirit.
d. Coordinated transportation through local CBOs and churches to assist community and program participants in getting to Consortium meetings.

The consumer voice was measured through a series of community surveys that included questions on awareness and effectiveness of the local consortium, questions about the problem of infant mortality in general and feedback on how the local system is functioning in addressing the problem pregnancies and births. Ongoing assessments from the consumers were infiltrated throughout all processes of the Consortium. Consumers were incorporated on all committees, boards, and hiring of Northeastern Baby Love Plus staff. Comprehensive evaluations were done to measure what are the overall desires/ needs for the consumer and her family.

7. Consumer and Community Involvement with Decision-Making Highlights

Historically, consumers have not had a voice in the design and implementation of local programmatic efforts. Local and state entities have a history of not being inclusive of consumers and hearing and respecting their voice. Some consumers feel that they lack the knowledge in MCH issues to make a difference. The Regional Network Manager provided orientation for new consortium members. Each member received an orientation packet that included by-laws, member responsibility, committee structure, meeting schedule, and general information about MCH efforts. There was follow up with consumers who missed meetings to ascertain the cause and bring them up-to-date on meeting issues. While the full consortium has a standard meeting time and location, committee meetings rotate between counties to allow for greater consumer participation. The standing committees determined their time and meeting place in order to meet at the convenience of the consumer members.

The Annual Healthy Start Training Institute, sponsored by the Regional Consortium, is the largest training event of the NC Baby Love Plus Program. The Training Institute is a high profile event that provides consumers and community members the opportunity for front-line participation in the NC Northeastern Baby Love Plus Program. The Training Institute was the opportunity to bring consumers, community members, faith, social, and civic organizations, and health and human service providers together for skill-building and sharing. The Training Institute is one of only a few state-wide conferences that provide such a mixture of participants. There was an average of 400 individuals including children at each Training Institute.

3rd Annual Healthy Start Training Institute	July 26 – 28, 2000
4th Annual Healthy Start Training Institute	July 25 – 27, 2001
5th Annual Healthy Start Training Institute	July 30 – 31, 2002
6th Annual Healthy Start Training Institute	July 17 – 19, 2003

Consumers and their families also benefited from attending Family Leadership Development Retreats that focused on issues that affect their daily living. Training was targeted to enhance the skills of the consumers (empowerment, finance, health care access, advocacy, and parenting). The Family Leadership Development Committee of the Regional Consortium planned and hosted the retreats. An average of 25 families attended each of the training retreats.

Family Leadership Development Retreat	June 2, 2001
Family Leadership Development Retreat	May 4, 2002
Family Leadership Development Retreat	February 8, 2003

Additionally, consortium members benefited from their involvement in the Board Development Retreat. This was an opportunity for consortium chairs, committee chairs, and others to engage in training opportunities around leadership development. The focus was on further development of the regional efforts, retention of members, and improvement in advocacy skills. The end result of the Board Development Retreat was that consortium leadership, including consumers, gained valuable skills in program advocacy that they were able to put into use time and again in advocating for continued funding of this Healthy Start initiative. The Regional Network Manager also met with individual members to discuss their involvement and contribution to the consortium.

8. Utilizing Consumer Suggestions

With the growth of the Regional Consortium came a change in roles. In addition to providing oversight services, the Regional Consortium undertook a greater responsibility for program development. The Regional Consortium made several decisions that refocused activities as well as financial resources. The most visible representation of the Consortium's input into budgetary matters was with the community sub-contracts program.

The suggestions and input provided by consumers were ranked and then prioritized based upon that ranking. These priorities where then integrated into the action plan for activities carried out by the consortium. These activities most notably appeared in the form of trainings that were designed to enhance the overall advocacy skills of the consumer, particularly the Family Leadership Development Retreat and the Healthy Start Training Institute.

Consumers were also intricately involved in:

- Planning and implementing the Health Start Training Institute and
- Planning and implementing the Family Leadership Development Retreats
- Developing the consumer reimbursement policy to facilitate consumer participation in meetings and training sessions
- Hiring staff (local and state)

- Grant development and submission for annual continuation applications and also the latest competitive grant cycle (2004 - 2008).

E. Sustainability

1. Efforts with Managed Care and Third Party Billing

Healthy Start funds were maximized through Medicaid reimbursement for case management services for prenatal care (MCC) and children with special health care needs (CSC). The two project area health departments have the ability to recoup prenatal case management expenses for pregnant women through sixty days postpartum. MCC billing provided nearly $2 million of in-kind donations annually toward grant efforts.

2. Major Efforts to Continue Project without Healthy Start Funding

The Northeastern Regional Consortium held discussions throughout the funding period on the merits of becoming 501(c) (3) non-profit organizations. By-laws were developed and articles of incorporation are in place.

3. Ability to Overcome Barriers or Decrease Negative Impact

On the local level, the Community Health Advocates and especially the Network Liaisons are responsible for sustainability through creating linkages that will continue program components beyond the funding period. This is most notable through outreach to

III. Project Management and Governance

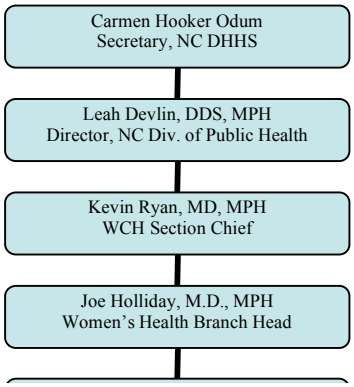
A. Structure of Project Management

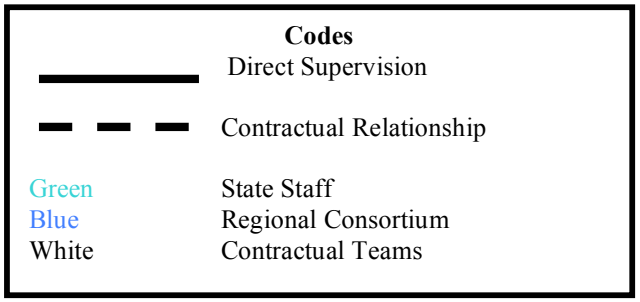
The administration and management of Northeastern NC Baby Love Plus throughout the funding period continued to be with the Department of Health and Human Services, Division of Public Health, Women's and Children's Health Section, the state's Title V agency. Dr. Kevin Ryan is the head of the Women's and Children's Health Section. Dr. Joe Holliday is the head of the Women's Health Branch. The Perinatal Health and Family Support Unit is within the Women's Health Branch. Belinda Pettiford, former NC Baby Love Plus Project Director (1999 – 2000) is the Perinatal Health and Family Support Unit Supervisor. Judy Ruffin served as the Program Manager during the entire funding period, 2000 - 2003. Ms. Ruffin was housed within the central office in Raleigh, NC.

Jerry Hankerson was the other state staff assigned to the project. Mr. Hankerson assumed the duties of Northeastern Regional Network Manager on 02 January, 2001. The Regional Network Manager served as the liaison between the Women's and Children's Health Section and the consortium and local agencies. This position reported to the Program Manager. The position was housed in the Eastern Regional Office in Greenville, NC.

Throughout the life of the program, the grantee organization partnered with the local health departments within the project area to hire local staff to carry out many of the program activities. Seven full-time equivalent CHA positions were maintained as well as 2.0 full-time equivalent Network Liaison positions.

NC Northeastern Baby Love Plus Organizational Chart 2000 - 2003




Codes
Direct Supervision
Contractual Relationship
Green
State Staff
Blue
Regional Consortium
White
Contractual Teams

B. Resource Availability

The WCHS, the grantee organization, has extensive experience in administering a complex array of statewide programs and correspondingly experience with large-scale fiscal management of such programs.

C. Changes in Management and Governance

There were no changes in management and governance of the project during the funding period. There was no staff turnover at the state level. The Women's and Children's Health Section contracted with three (3) local health departments and one (1) health district for local implementation of the project. Funding was provided to the local health departments to support the hiring of local staff (Network Liaisons and Community Health Advocates) to carry out the project. There were no changes in the Network Liaison positions. There was minimal staff turnover in the Community Health Advocate positions.

D. Process for Distribution of Funds

The process for distribution of funds was developed during the project planning stage. Staff from the Women's Health Branch (of WCHS) met with leaders from the local health departments and Northeastern Regional Consortium (both consumers and community representatives) to discuss program requirements and funding availability and restrictions in an effort to prioritize projects for Northeastern NC Baby Love Plus. Annually, the local health departments were requested to provide salary requirements. Operating expenses for the local health departments were provided using standard state formulas. Funds were then distributed to the local health departments through the state's Local Health Department Agreement Addenda process. Funds were distributed to other contractors through a Request for Application process. Generally, all contracts were on a July – June fiscal year.

E. Additional Non-Healthy Start Resources

The major non-Healthy Start contributor to Northeastern NC Baby Love Plus was the state's Baby Love Program. Baby Love, through Medicaid billing provided nearly $2 million of in-kind donations annually toward grant efforts. Other contributors to the support of the program (in-kind and financial) were the NC Chapter of the March of Dimes, the NC Office of Minority Health and Health Disparities (OMHHD), and the NC Healthy Start Foundation. These organizations provided program support in the form of conference sponsorship, staff skill-building, technical assistance, and general program collaboration around health disparity efforts.

F. Cultural Competency of Contractors

The Women's and Children's Health Section is firmly committed to racial disparity prevention. A step toward this goal is cultural competency of staff and contractors. Northeastern NC Baby Love Plus state and local staff was required to participate in continued cultural competency training. Northeastern NC Baby Love Plus, in partnership with the OMHHD, conducted the cultural diversity initiative for the local health departments and community-based organizations in the project region. Additionally, all Northeastern NC Baby Love Plus contracts stipulated the provision of culturally appropriate family-friendly services including insuring that all health education materials were culturally appropriate.

IV. Project Accomplishments

A. Major Strategies with Lessons Learned

See Project Period Progress Report below.

Model: Case Management with Outreach

Objective	Strategy Activity	Progress
CM1: By May 31, 2003, increase the number of participating infants who turned one year of age during the reporting period who were appropriately immunized. Baseline: 1997 data revealed that 79% of infants seen at the health department were age-appropriately immunized (latest data figures). CM2: By May 31, 2003 increase the proportion of pregnant women in the target counties who initiate prenatal care in the first trimester of pregnancy. Baseline: During 1998, prenatal care was initiated during the first trimester for 74% of African American births in the region.	Aggressive outreach tailored to individual communities. • Execute contracts with four local health departments to hire Community Health Advocates (CHAs). • Hire CHAs to provide education and casefinding services. • Provide intensive training on outreach and MCH issues. • Conduct bi-monthly team meetings with CHAs for additional skill building, sharing of ideas, and networking opportunities. • Execute contract with the North Carolina Healthy Start Foundation for public awareness campaign. • Convene Public Awareness committee of Regional Consortium. • Develop and implement media plan with guidance from the Regional Consortium. •	Signed Agreement Addenda (contracts) continuously in place with Nash, Northampton, Halifax, and Hertford-Gates District Health Departments. The department hired 7.0 FTE Community Health Advocates (CHA) who provided intensive outreach to the targeted communities. The Regional Network Manager convened monthly team meetings to provide skill-building and networking opportunities for local staff. During the 2001-2004, the staff made 13,924 contacts through community group settings and another 8,892 contacts through targeted group settings, for a total of 22,816 contacts in the community through group meetings. The total number of people reached through *Baby Love Plus* outreach efforts in this time period was 63,825 individuals or an average of about 1,330 people per month. Staff person hired for Public Awareness Campaign.

Objective	Strategy Activity	Progress
OM2: By May 31, 2003, increase the number of women residing in the project area who are enrolled in outreach services. Baseline: This is a new service. Anticipate 8,000 contacts per year.		Public Education/Awareness Committee of Regional Consortium in place throughout funding period More than 150 neighborhood and 190 community outreach events were held annually, which represents an average of 14 events per month in each county. The outreach team reached 32,248 individuals through group events during the project period. There was a shift in the focus of the program away from a general community approach to a more targeted and intensive approach encouraged CHAs to provide outreach to women of reproductive age likely to have a need for perinatal-related referral. Of the total number of individual (primary) contacts made, 4,422 (6.0%) were referred for some follow-up service. This represents over 1,000 referrals per year. However, only a small proportion of these referrals was for a service related to perinatal care — prenatal care, maternity care coordination, WIC, or family planning. Only 10% of all the 4,422 referrals were for prenatal care, and only 5% were made to Maternity Care Coordination. Other referral needs of clients include Department of Social

Objective	Strategy Activity	Progress
		Services (7%), Family Planning (8%), Well-Child Care/Immunizations (5%), and WIC (7%).
CM3: By May 31, 2003, reduce the incidence of low birthweight, very low birthweight, and small and large for gestational age live births in the target area counties. CM2: Increase the proportion of participating women pregnant women in the target counties who initiate prenatal care in the first trimester of pregnancy. OM2: By August 31, 2000, increase service utilization of families residing in the project area who are enrolled in facilitating services. Baseline: To be determined after further assessment in year 01. Overall goal is to assist 250 families.	Providing facilitating services to pregnant and parenting families. • Execute contracts with four local health departments to provide facilitating services. • Develop a subcommittee of the Regional Consortium for additional assessment of existing facilitating services. • Conduct meetings with existing providers of facilitating services to review program enhancements. • Set-up and continue coordination of additional facilitating services in the project area. (• Conduct meetings with health and human service providers (public and private) to increase awareness of facilitating services.	Each county instituted new transportation services for their maternity clients. During the project period, 830 women were provided with transportation services The Regional Network Manager and Network Liaisons continually assessed each county transportation system. By contract, each local health department was required to conduct a bi-annual review of their system. Each department was also required to have a consumer participant on the review panel. Northeastern Baby Love Plus staff trainings were offered bi-monthly, (especially for the Maternity Care Coordination team) and were designed to enhance outreach efforts, particularly by strategizing plans of actions for each county.

Model: Consortium

Objective	Strategy Activity	Progress
CM4: By May 31, 2003, increase consumer participation in local and regional consortia. Baseline: (Year 1 – Regional consortium consisted of 35% consumers. Year 2 goal – 40%) CM1: By May 31, 2003, increase the capacity (knowledge and skills) of consortia members through local trainings. Baseline: to be determined after each training session.	Recruit consumers/ family members from priority populations. • Job description for Regional Manager position developed and submitted to State Personnel. • Contracts with two local health departments to hire 2 Network Liaisons. • Regional Manager of the Regional Consortium hired. • Two Network Liaisons hired to coordinate local county efforts. • Conduct assessment and interest survey to determine training needs. • Provide childcare, transportation, and nutritious supplements for consortia meetings and trainings. • Conduct skill-building/training session during every other regional and local consortium meeting.	Job description developed July 2000 and submitted to State Personnel for approval. State personnel approved job description for Regional Network Manager in September 2000. Regional Network Manager hired by January 2001. Position held by Jerry Hankerson throughout the funding period. Both Network Liaisons were in place by October 2000. LaTasha Sledge and Hallie Peace held the positions remained stable throughout the funding period. Transportation and Childcare provided as requested. Consumers reimbursed for transportation & childcare. Nutritious supplements provided at each meeting. Training sessions included: • Annual Healthy Start Training Institute • Perinatal Forum on Racial/Ethnic Disparity • Asset Mapping Conference • Other skill-building to be integrated into bi-monthly meetings.

B. Mentoring and Technical Assistance

While Northeastern NC Baby Love Plus did not participate in mentoring site visits, they did participate in a reciprocal mentoring relationship with Healthy Start Corps (sister Healthy Start project). There were numerous phone and face-to-face visits with the project director and staff of Healthy Start Corps. There were annual partnership development conferences, "Building Bridges," jointly sponsored by NC Baby Love Plus (Eastern, Northeastern, and Triad Programs), Healthy Start Corps, Healthy Beginnings (NC's minority infant mortality prevention program).

Northeastern NC Baby Love Plus also collaborated with the NC Fatherhood Development Advisory Committee and others to sponsor the "Men Are Nurturers, Too! (M.A.N.2) Community Collaborative Conference. Each year, the Regional Consortium selected a father-of-the-year who was recognized at the annual conference along with his family.

Northeastern NC Baby Love Plus in partnership with the Regional Consortium provided technical assistance for consumers, community members, and local partners, including local health departments, community-based organizations, and health and human service organizations around a variety of issues. The most notable of activities was the Annual Healthy Start Training Institute. The Training Institute is a skill-building conference for consumers, community members, and health and human service providers on family and child health issues. The Training Institute was the opportunity to bring all partners together to discuss issues around perinatal health and community development. A full-scale children enrichment center was erected at the Training Institute so that the entire family could participate in the program. Approximately 400 adults and 100 children participate in the annual event.

Consumer participants received specially designed training around family leadership. The Family Leadership Development Committee of the Regional Consortium identified the need to provide a smaller skill-building workshop for consumers around leadership, communication, and program ownership. Annually, throughout the life of the program, the committee hosted the Family Leadership Development Retreat for consumers and their partners and children. The intended purpose was to give consumers greater confidence and ability to fully participate in the work of the Regional Consortium. Approximately 75 families attended each Family Leadership Development Retreats.

V. Project Impact

A. Systems of Care

1. Approaches Utilized to Enhance Collaboration

One of the early-identified problems was lack of community involvement in decision-making processes. The Norteastern Regional Consortium was viewed in part as a vehicle for ensuring community and especially consumer involvement in decision-making aspects of the project. Regional Consortium by-laws stipulated consumer involvement in all policy and decision-making activities of the Regional Consortium. The Regional Consortium was continually involved in the development of the program, including the inclusion of activities to develop within the program's budget.

One of the most notable activities supported by the Regional Consortium was the erection of the Community Subcontracts (mini-grant) program. The program was housed within the Regional Consortium to also ensure a regional versus a state focus on the program and to ensure community involvement and ownership. The program was designed to empower the Regional Consortium in the decision-making aspects of the project, to build and maintain interest in the program, and to provide an opportunity to see immediate, tangible benefits of the program. Relationships were forged through community subcontracts with health and human service organizations, faith, social, and civic organizations, and community-based organizations in the project area that have remained throughout the life of the program.

An added goal of the community subcontracts program was that it helped to identify and support sustainable infrastructures in the project area communities. The NEBLP community subcontracts program targeted community-based and public organizations with strong roots in minority communities and supported them in implementing innovative approaches to infant mortality prevention.

Prior to the annual grant application deadline, a pre-application workshop was held for prospective applicants. Information about the NEBLP Program was presented and the Request for Applications was distributed. See Attachment A for a copy of the RFA. Prospective applications also received step-by-step instructions on how to complete the application form and were given the opportunity to meet one-on-one with NC BLP Program representatives to review their project ideas and ask questions.

2. Structural Changes

All Northeastern NC Baby Love Plus contracts mandated consumer involvement in all decision-making efforts, including the hiring of staff and development of policies. Additionally, contracts stipulate the provision of culturally appropriate family-friendly services. Local health departments Agreement Addenda have such wording included:

- Coordinate with the Northeastern NC Baby Love Plus Program Manager in the selection of program staff and include local participation (consumer and community) in selection of program staff. Staff must meet qualifications as set forth by the NC Baby Love Plus Program.
- When hiring Baby Love Plus staff, including Network Liaisons, Community Health Advocates and Family Care Coordinators, include a local consumer on the interview team as well as a representative from the Division of Public Health's Perinatal Health and Family Support Unit. All staff must meet the minimum qualifications set forth in the attached position descriptions.
- Adopt family-friendly policies and procedures (especially in regard to childcare and transportation) to support consumer participation in local Baby Love Plus activities.
- Establish local task forces to a) assess policies and procedures for tracking and following up on missed maternity, family planning and well-child appointments, b) develop recommendations for improving tracking and follow-up systems, and c) advocate for systems changes.

- Mobilize community stakeholders to engage in collaborative efforts to improve maternal and infant health through a regional community-based, consumer-driven coalition.

3. Key Relationships

The WCHS and hence Northeastern NC Baby Love Plus networked with and maintained collaborative linkages with a wide range of state and local service providers and resource systems to plan and implement perinatal health initiatives in the project region and statewide. Additionally, the Northeastern Regional Consortium participants included a variety of social, civic, faith organizations as well as a host of health and human service organizations and educational institutions. In addition to the two local health departments, active collaborative partners included:

- County Departments of Social Services
- Faith organizations (local and statewide)
- Head Start
- Community Development Corporations
- Local Mental Health Agencies
- Smart Start[1]
- First Start[2]
- March of Dimes

4. Impact on the Comprehensiveness of Services

Through the work of the Community Health Advocates and Network Liaisons, relationships have been fostered and/or strengthened with the local Departments of Social Services, private providers, and other health and human service providers.

Another positive impact of the program has been the fostering of intra- and inter-agency collaboration. Northeastern NC Baby Love Plus had a strong hand in the local health departments maternal and child health programs working in concert with each other. Even within the health departments there was limited collaboration between programs with similar focus. Northeastern NC Baby Love Plus program with its various integrated models was a strong impetus for working as a team.

5. Impact on Client Participation in Evaluation

The evaluation team worked with the Regional Consortium to identify the community needs and the target communities. The evaluation team met with the Regional Consortium on a quarterly basis to gain input into the evaluation activities and to gain input about community changes that affected the program. Regional Consortium members also participated in community surveys. The results of the surveys showed the need to:

- Intensify community outreach around infant mortality issues and perinatal services
- Amplify consumer voices in overall program development
- Collaborate more with community leaders

[1] Public-private initiative for children age 0 – 5 to prepare them for school through the provision of childcare, health services, screening, and other wrap-around services

[2] Pre-school readiness initiative within the NC Department of Public Instruction.

B. Impact to the Community

A common vision developed amongst consumers, community members, and agency representatives in regards to addressing infant mortality and improving the health of mothers and babies. In consumer, community, and consortium surveys, participants cited common goals and missions around services and support. The Regional Consortium adopted a vision statement at the beginning of the program. That vision spoke to the sentiment addressed by survey participants.

Healthy Start Baby Love Plus

Healthy Communities . . . Healthy Babies . . . Healthy Start

Vision Statement

Babies will have a healthy start in life by:

a. being born to parents who have carefully thought about and are prepared for the responsibilities of parenthood and into families that will be loving, supportive, and nurturing;

b. living in communities that embrace and promote the concepts of family, community support, and love; and

c. having access to essential health, social, economic, and environmental resources.

Making Room at the Table

Agencies and organizations had limited experience working with consumers before Northeastern NC Baby Love Plus. The program was an opportunity for agencies to recognize and respect the skills and abilities of consumers. Initially, the agencies had to be coaxed to include consumers at the decision-making table. As time progressed with the program, the same agencies that balked initially understood the immense benefit to including consumers in decision-making activities.

Employment Opportunities

The outreach staff has been the keystone of program success. The CHAs were seen as the first and integral step in recruiting and retaining women and children in health services. The value and ability of the outreach workers can best be seen in their work over the past years. Throughout the funding period, the CHAs were involved in a number of traditional and innovative approaches to community outreach. Northeastern NC Baby Love Plus identified more than forty different types of activities that the CHAs were involved with their community outreach efforts. Throughout the project period, the CHAs averaged 20,000 contacts annually. In addition to providing intensive community outreach, the CHAs also provide outreach to

organizations (civic, social, faith, etc.) in the project counties to engage them as partners in infant mortality prevention efforts.

Northeastern NC Baby Love Plus provided funds to the local agencies to support seven (7) full-time Community Health Advocates. Additionally, funds

C. Impact on the State

Northeastern NC Baby Love Plus is unique in that the grantee agency, Department of Health and Human Services, Division of Public Health, Women's and Children's Health Section (WCHS) is the location of the State Title V program. With that in mind, WCHS took this as an opportunity to strengthen its relationship with its other public health partners. This has included local health departments, and community-based organizations, including civic and faith entities. This has been achieved by several means.

First, staff employed by local health departments implemented the majority of the direct service components, i.e., outreach and prenatal case management. Contracts were initiated with local health departments to hire Local Coordinators (Network Liaisons) and Community Health Advocates (Outreach Workers). These staff members were integral component of this effort. This helped to insure that services were enhanced and not duplicative.

Next, the development of the community subcontracts component broadened the relationship and included new health partners. This was achieved initially by the release of a request for applications process. This allowed community-based organizations the opportunity to apply for funding to support programs that enhanced Northeastern NC Baby Love Plus effort. Activities have included fatherhood involvement, preconceptional health education, support networks, and case management for non-Medicaid women. The Regional Consortium provided leadership and guidance in the selection of the community subcontracts. Representatives from these organizations attend the consortium meetings and gave updates on program activities, including challenges and successes.

As the Title V agency, WCHS also had strong networks with state Medicaid, the Division of Medical Assistance which included collaboration with statewide Baby Love Program (on which the NC Baby Love Plus Program was built). This included providing Medicaid Coverage for Pregnant Women, along with the statewide Maternity Care Coordination (MCC) program.

WCHS also collaborated with the state Medicaid program in the implementation of NC Health Choice (SCHIP). NC Health Choice is administered with through the state Medicaid program along with Blue Cross/Blue Shield Insurance. WCHS is responsible for the outreach components of this program. TBLP provided intensive outreach to families to ensure they were aware of and enrolled in the program.

WCHS also continued to strengthen relationships with the Office of Minority Health and Health Disparities (OMHHD). During the funding period, Northeastern NC Baby Love Plus partnered with OMHHD in the development of *Elements of the Past – Implications for the Future*, the third component of the cultural diversity training curriculum developed by OMHHD. This third

component focused on African-American health disparity. This curriculum is now an established part of the state's cultural diversity training program.

D. Local Government Role

The Northeastern NC Baby Love Plus Program is carried out collaboratively with the local health departments and community based organizations in the two county project area. The local health departments are all part of their local county government system.

E. Lessons Learned

Three main lessons were learned during the original funding cycle and were incorporated into the program design of the 2000 - 2003 funding cycle. The lessons were woven into program and continuously reviewed.

Lesson 1. The community should be involved in training assessment, design, and implementation process.

In order to get consumer and community input, six types of needs assessments were used to determine training needs: Customer Satisfaction Surveys, Focus Groups, Provider Listening Sessions, Program Staff Needs Assessments, Regional Consortium Surveys, and Community Partners Site Visits.

Consumers and community members assisted the evaluation team in implementing many of the needs assessments tools. Consumers and community members were also involved in the program and policy development for the program. TBLP worked to insure that policies were in place with program partners and contractors that required the consumers to be in program and policy development efforts.

Lesson 2. Families should receive training so that they can adequately participate in the activities and planning of the program.

The Training and Development Committee of the Regional Consortium used information from the needs assessments to develop training topics for the bi-monthly Regional Consortium meetings. Training topics incorporated into Regional Consortium meetings focused on women's health best practice issues (family planning, folic acid, HIV/AIDS, smoking, domestic violence, nutrition, immunization, etc.). Local experts provided the training. Information from the needs assessments was also used to plan the Family Leadership Development Retreat and Annual Healthy Start Training Institute.

The Annual Healthy Start Training Institute was a two – three day conference in which program participants, the general community, and providers have the opportunity to learn about issues related to women's and children's health, and have the opportunity to dialogue about community development issues. Consumers and community members were integral to the planning for the Family Leadership Development Retreats and the annual Healthy Start Training Institute.

The Family Leadership Development Retreat was a more intimate training environment for program participants and their families. Retreat participants had the opportunity to learn and practice skill-building around personal and community advocacy and empowerment issues. An average of twenty-five families participated in the annual retreats with training topics covering financial management, stress and anger management, and effective family communication. Those families invited to the retreat had minimal participation with the Regional Consortium beforehand. Since the retreat, they have actively attended meetings and other events. The Family Leadership Development Retreat is a feeder for the Healthy Start Training Institute.

Lesson 3. Providers should receive training so that they are more receptive and accessible to families.

Program staff was able to document the need for customer service training for providers through information received from consumer listening sessions. Project area local health departments participated in a Customer Service Workshops. The workshops focused on visualizing the needs of customers, developing positive response to needs, and establishing a customer service model that works for the individual agency.

Local health department staff and community-based organizations participated in two levels of cultural diversity training. Level one training was foundational training aimed at increasing awareness and knowledge base regarding cultural diversity and its implications for culturally competent service delivery. Level two training was African-American culture-specific training. The training was designed to provide participants with the awareness and knowledge about African Americans and their cultural experiences, thereby better preparing health and human service providers to more effectively address the health disparities that exists between African Americans and Whites. The training was provided in partnership with the NC Office of Minority Health and Health Disparities.

VI. Local Evaluation

Project Name: Northeastern NC Baby Love Plus
Title of Report: Impact Report for HRSA NC Healthy Start — Baby Love Plus
Author(s): JL DeClerque, DrPH - Principal Investigator, UNC Sheps Center
Ellen Shanahan, MA – Project Director, UNC Sheps Center

Section I. Introduction

Local Evaluation Components

A. *Impetus for local evaluation*: The evaluation of North Carolina's *Baby Love Plus* (BLP) Program to address racial disparities in infant mortality in the Northeastern region of North Carolina was a collaborative approach to program evaluation that included a combination of traditional and innovative research strategies. It built on the study design, data sources and field methods established during the first cycle of the *NC BLP Eastern and Triad Region Programs*. Although the evaluation component was contracted to the UNC Sheps Center for Health Services Research, both the process of its design and the conduct of the plan during the program has been in close collaboration with the *BLP* management team as well as the network of field staff involved in its implementation.

B. *Brief history of the evaluation's inception and focus*: The focus of the evaluation was on the perinatal systems of care, the services provided to Healthy Start participants and their families, and the health status of those receiving services funded by Healthy Start. However, in addition to the customary tracking of perinatal services in the project counties and documenting numbers of participants served, the evaluation played an active and integral role in providing recommendations to the *Northeastern Baby Love Plus* program and staff for continuous quality improvement. By adding several new system-level assessment tools and expanding the range of community surveys, the evaluation team provided rapid turn-around of survey results that were useful for program planning and management. The evaluation team worked closely with the *Northeastern Baby Love Plus* management team to review program goals and helped identify new needs voiced by consumers, local providers and program staff. The evaluation team worked closely with State and local staff in the development of an interconceptional care component, designing screening and assessment tools (Attachments E1 – E4) as well as the design and implementation of service tracking that has been implemented in the new program phase for the region. The evaluation used comparison counties and a pre- and post-test approach so that the impact of the *Northeastern Baby Love Plus* program for participant families and systems of care could be assessed. The evaluation was also designed to assess community involvement and sustainability of program efforts. As such, the *Northeastern Baby Love Plus* Evaluation Plan, in its final form, encompassed features of formative evaluation, process, as well as outcome evaluation designs.

C. *Type of Study* The local evaluation plan included three distinct, but related components: 1) a target versus comparison area program impact; 2) a program recipient versus non-recipient comparison within the target area; and 3) a community wide assessment in the target area of the sense of ownership and responsibility for the problem of infant mortality and general community

wide development as a result of the *Baby Love Plus* Program. In addition, all required GPRA data elements were generated as required by HRSA. The evaluation focused on each of the funded components, as delineated by the Federal Healthy Start Office. In the NC Northeastern program, they were *Case Management (including transportation)*, *Outreach Activities, Education and Training*, and *Consortium Activities.*

Key Questions/Hypotheses

The local evaluation was organized by three broad questions and three main hypotheses as described below. The four Healthy Start models in the region were each seen as a means to achieve the overall objectives of improving the birth outcomes and perinatal services, especially for area African-American women.

1. Does the Healthy Start *Baby Love Plus* Program improve birth outcomes (including diminishing racial disparities), health services provision, and service integration in the Program's target area, compared to a non-program comparison area of the state?
2. Do target area women who received Healthy Start *Baby Love Plus* special services (care coordination, outreach, and education and training) have improved birth outcomes (including diminishing racial disparities), health services utilization, and service integration compared with other women in the target area who do not receive these services?
3. Does the Healthy Start *Baby Love Plus* Program impact the target community's sense of ownership, responsibility for and understanding of infant mortality problems and poor birth outcomes, as well as impact the target community's development through the activity of regional and local consortia and other community-based activities?

Three main hypotheses guided the evaluation:

- Community capacity, responsibility for, and ownership of infant mortality reduction efforts will increase during the project period.
- Enhanced BLP services will result in more appropriate and more valued service provision.
- Birth outcomes in the project area will improve, with reductions in disparities, more rapidly than in comparison counties.

Together, these three hypotheses were assessed taking into consideration the expected levels of program impact, highlighting the community-based focus of the Program, while realizing the need to track the diffusion and effect of the program for individual families in the study area.

Section II. Process

A. Key Features of the Northeastern Baby Love Plus Evaluation

Evaluation was used as a Tracking Tool: Implementation and Outcomes

A core function of the *Northeastern Baby Love Plus* evaluation was documenting that the interventions happened as proposed. As such, activities related to each model were tracked and the number of services provided to Healthy Start program participants recorded and summarized annually for evaluation progress reports. As described more fully below, descriptive data for each program participant and aggregate data for the study region were reported on birth

outcomes, use of perinatal services, care coordination and other support services offered through the State's maternity case management (*Baby Love*) efforts.

Evaluation was used as a Planning Tool

In addition to documenting implementation and outcomes of the *Northeastern Baby Love Plus* program, the evaluation assessed key areas for planning and program development. The first task of the evaluation was to work with the Regional Consortium to conduct a *local survey* to: 1) identify where problems are concentrated; 2) examine opportunity gaps for addressing the problems; 3) work with the Regional Consortium to modify or shift efforts to close the gaps; and 4) engage the Regional Consortium in monitoring the problems and the solutions that they have a stake in. In addition to the initial assessment, the evaluation team assisted the Regional Consortium with their Local Health Action Plan, providing *Northeastern Baby Love Plus* staff with feedback from periodic surveys and interviews, and reporting on the extent of consumer satisfaction with the scope, quality and availability of services. These data were intended to provide the foundation for effective and continuous quality improvement in the *Northeastern Baby Love Plus* Program.

Evaluation was used as a Management Tool

To aid with program management, the evaluation team summarized information from administrative data collected on various components of the project. This included summaries of data collected on tracking forms used by *Northeastern Baby Love Plus* outreach staff indicating the number of groups reached, number of participants contacted, types of needs that were identified and the number and range of referrals that were made. Management issues related to program priority areas or aspects that needed strengthening were indicated through regular data review meetings with BLP leadership staff.

Study Population

The target population for *Northeastern Baby Love Plus* was African-American families that included women of reproductive age residing in key neighborhood areas of the program area, Nash, Halifax, Northampton, Hertford, and Gates counties identified as risk zones for poor birth outcomes. The study population for evaluating this Program were residents of these counties who were Medicaid recipients for prenatal, delivery, and post-partum care and enrolled in the State's maternity care coordination program (*Baby Love*) and who subsequently obtained well-baby care for their infants. Inclusion criteria were resident births listed on State vital records from the study counties and who had a Medicaid claim paid for maternity care coordination during the period January 2001 through December 2004. Due to a lag in vital records and the need to allow for both gestation time and subsequent morbidity/mortality in the first year of life, a full range of services, birth outcomes and post-partum data will be examined for a subset of women and their infants (i.e., those who delivered between January 2002 and December 2003, a 24-month cohort). However, partial data for all families who participated in *Northeastern Baby Love Plus* over the four-year study period are also examined. Preliminary results are included in this report.

Overall Approach and Levels of Analysis

The *Northeastern Baby Love Plus* evaluation served several functions and answered questions across multiple levels of the Program. At the most basic level, *Northeastern Baby Love Plus* managers and field staff received useful feedback regarding administration and operation of the program on an on-going basis. At the regional level, the perinatal services sector were given useful feedback about the quality of prenatal and post-partum care, client satisfaction with service delivery, perceived barriers to care and suggestions for improving systems of care. At the program level, the evaluation is in the process of measuring the success of the overall program portfolio and of each specific component using process, outcome and impact measures at four levels: community, systems, services and individual.

The following table identifies the various levels of analysis for both target and comparison areas which will be used in the evaluation and will be referred to in this report.
As will be explained later, data across all levels of analysis are used to evaluate the program, from secondary data state administrative records for levels $A_{1,2}$,$B_{1,2}$, and $C_{1,2}$, (through identifying markers)..

Table 5
Levels of Analysis: Target and Comparison Areas

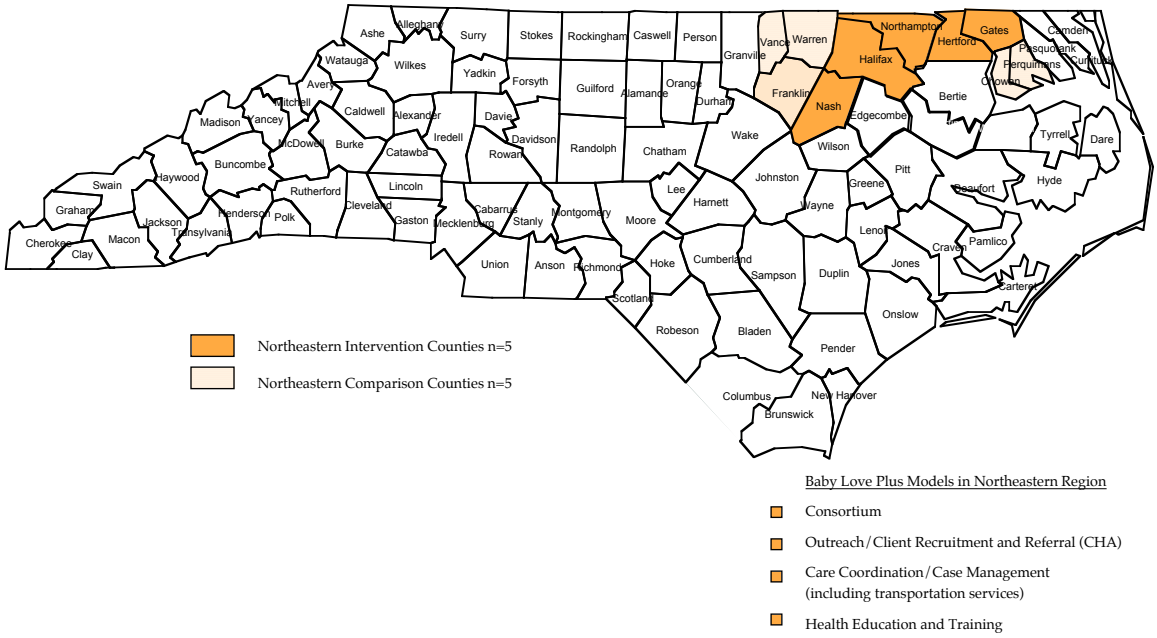
Population Assessed	Measure	Target Area	Comparison Area
Community at large	Total area births	A_1	A_2
Medicaid community	Medicaid births	B_1	B_2
BLP clinical Prenatal Participants	Medicaid births with care coordination (Maternity Care Coordinators- MCC)	C_1	C_2
BLP community participants	Education and Training (Community Health Advocates- CHA)	D_1	D_2
BLP community participants	Consortia activities, community awareness surveys	E_1	E_2

The evaluation focused most intensively on levels C and D Medicaid births with Maternity Care Coordination and the Outreach and Training to and for the Baby Love plus target population. The impact of the Program hopefully should also be apparent at other population and Medicaid participation levels (A, B, and E) within the target counties.

Evaluation Design

The evaluation design involved analyzing birth outcomes and service utilization before and after the intervention both within the project counties and between the project and comparison counties. This is to control for possible secular trends and within-county effects due to parallel efforts in the project area or region. The map below depicts the comparison counties selected for the study (as well as the other regions in NC where Healthy Start programs are operating). The comparison counties were selected based on careful analysis of population demographics, proportion of births to Medicaid mothers, levels of enrollment in the *Baby Love* Program and prevalence of standard perinatal risk factors.

NC Healthy Start *Baby Love* Plus Program
Northeastern Region
Intervention and Comparison Counties



B. Procedures for Conducting Local Evaluation

Data Sources

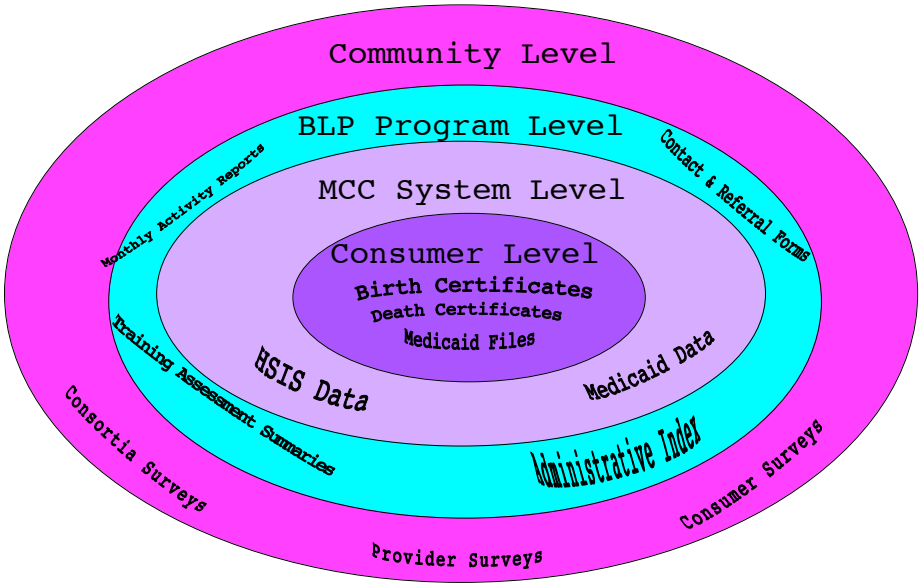
North Carolina has one of the most comprehensive State perinatal databases in the U.S. It contains sufficient information and detail to examine both broad population trends, and detailed services, by name, of Medicaid participants. Annually, a North Carolina "Baby Love" data file is created that augments the state's birth certificate data files. This file contains person-specific indicators of public program utilization of Medicaid, WIC, MCC, and County Health Department services (plus some summary details about their participation characteristics); and, most importantly with personal program identifiers to link them with the more detailed administrative data systems of those public programs.

A variety of data sources have been used in the evaluation effort. They have been selected (or developed in cases where no appropriate data existed) to complement one another and to meet the needs of each level and group with a state in the Program. Each of the data sources is described in full detail below. In sum, there were three sources of secondary data and three types of primary data that were used. Secondary data sources included: 1) the North Carolina *Baby Love* File that includes linked vital statistics; 2) the Health Services Information System (HSIS) that includes data on maternity clients and their children who received health department services; and 3) the North Carolina Immunization Registry. Primary data that were collected included: 1) s*urvey data* from the Regional Consortium, local providers (clinical, support and outreach), and Healthy Start consumers (maternity, family planning and well-child services); 2) *programmatic data* gathered on contacts made through outreach, Regional Consortium activities,

health education and training, and transportation services; and 3) s*ystems survey data* obtained through interviews with key informants to assess how well perinatal systems of care in the project area are working, and to document changes in interagency relationships.

Detailed descriptions of primary and secondary data sources are presented below according to the following levels of program assessment.

BLP Sources of Study Information



Secondary Data Sources

North Carolina Baby Love File: The North Carolina *Baby Love* File is a linked vital statistics (birth/death records) file that is merged with individual-level data from Medicaid claims files and local health department maternity and well-child service data. Annually, a *Baby Love* data file is created which augments the State's birth certificate data files. This file contains data on utilization of Medicaid-reimbursable programs such as WIC and maternity care coordination and includes summary data on participant characteristics. The file also contains program identifiers that can be linked to the more detailed data systems of each Medicaid-funded program. Data are available for selected demographic information, prenatal services and birth outcomes. Figures are very stable with only small variation from year to year. There is a delay of eighteen months (minimum) before data become available for any given birth cohort. Currently, the 2004 *Baby Love* file is being finalized by the North Carolina State Center for Health Statistics and is expected to be available by November 2006. All needed data is available for both the target and comparison counties, as these are statewide databases.

Health Services Information System: The Health Services Information System (HSIS) contains administrative and service statistics for maternity clients who received at least one prenatal visit at a local (county) health department and also information for their infants if they are receiving

HD related services. In addition, the HSIS database provides data on health services provision and integration, including MCC, post-partum women's health, well-baby care, and WIC services. The majority of the required GPRA items, including the case management data reporting measures, needs identified and needs met, and information on postpartum/family planning visits are derived from the HSIS Pregnancy Outcome Summary Report generated by the State Center for Health Statistics for each county. All *Northeastern Baby Love Plus* program participants (those enrolled in MCC) receive services from local public health clinics or private providers who accept Medicaid, and are included in these statistics. Data are reported as aggregate county-level data and summarized for the project area.

North Carolina Immunization Registry: The North Carolina Immunization Registry is a relatively new database with county-level aggregate data on vaccinations provided through health departments. The number of vaccines distributed and proportion of children immunized who are current for age can be obtained from this file; however, it is difficult to obtain client-specific data using this registry. Thus, we will report data aggregated by county rather than data linked to individual birth outcomes.

Primary Data Sources

Community Health Advocate Contact and Referral Logs: The Community Health Advocate (CHA) Monthly Contact and Referral Logs (Attachment B) summarize data collected by the CHAs on contacts and referrals made while conducting outreach activities. The CHAs fill out Daily Activity Logs that are utilized to prepare the Monthly Contact and Referral Logs that are then sent on to the evaluation team for data entry and analysis. The evaluation team entered the data on an EXCEL file and was able to provide information on total contacts, total referrals, reasons for referrals, types of agencies referred to, average number of contacts per month and average number of contacts per outreach worker and for the region.

***Transportation Services Tracking Logs*:** Facilitating Services data forms (see Attachment G) for tracking use of transportation services were used by all county maternal and child health team members, including the local *Baby Love Plus* Program staff, to report use of the transportation services. These forms were sent to the evaluation team at Sheps until 2003, at which point they were sent from the local county staff to the data coordinator in Raleigh. The data were entered into a tracking system designed to assign a unique person-specific identification number to each individual receiving a *Baby Love Plus* transportation service. This made it possible to distinguish multiple service use by any one individual. We were able to track unduplicated counts of project participants and therefore able to report number of services provided as well as number of families served.

Regional Network Manager's Report: The Regional Network Manager prepared a semi-annual report on Regional Consortium membership, meeting attendance, committee and subcommittee chairs, member status, and member participation and trainings held throughout the reporting period. Consumer participation was measured through the regional and local area Consortium in terms of the percentage of consumers represented; the similarity of the racial distribution of consumers to that of the overall project area; the percentage of consumers defined as active members of the Consortium; the percentage of consumers holding leadership positions; and the percent of project decisions affected by consumer input. The report also contained month-by-

month highlights of Regional Consortium activities. A copy of the Regional Network Manager's report form is included in the Attachment C.

***Administrative Indices*:** Straightforward checklists to determine the status of program activities were developed in the first year of the program period for: Regional Consortium, health education and training and program management (i.e., staffing, communication, technical assistance, contracting and leadership). Semi-annually, key staff and partner agency personnel were contacted by evaluation staff to determine if specific tasks were initiated, were in progress or had been completed. The results from these checklists were summed and provided as feedback to *Northeastern Baby Love Plus* staff and the Regional Consortium as part of continuous quality improvement efforts. The forms were discontinued in 2003 at the Program Manager's request

Community Surveys: (with BLP Consumers, Regional Consortium and Local Area Providers) Annual consumer, consortium and/or provider surveys(Attachments D, F)were conducted over the course of the project, beginning with a survey of the Regional Consortium in the first several months of project start up. The surveys were conducted individually, either face-to-face or by telephone, with the following constituents: *Northeastern Baby Love Plus* participants, local perinatal health providers and Regional Consortium members. These surveys were developed in conjunction with *Northeastern Baby Love Plus* staff and Regional Consortium members for use during the project period and were field tested and used successfully. The surveys were pre-programmed using BLAISE software onto laptop computers allowing data to be directly entered at the time of the interviews.

C. Measures Used

To assess the community a series of community surveys were implemented. We surveyed all current BLP-Northeastern Consortium members using the BLP-Northeastern Community Consortium survey instrument. Subsequent to that, consumers were interviewed in pediatric clinics throughout the project area using the BLP-Northeastern Consumer Survey (listed in Attachment D). Eighty-four surveys were completed covering Medicaid-clients from public and private clinic settings divided proportionally across the study counties. Again, there were no refusals, and all clients approached and determined to be eligible agreed to participate. A modification of the initial set of surveys was designed at the request of the Regional Manager and is in the process (Spring 2006) of being implemented. Its purpose is to obtain an update on suggestions for program improvements from local consumers, Consortium Board members and a range of community partners involved in perinatal health.

To assess the systems of care pertinent data were extracted from the consumer surveys related to satisfaction with prenatal, care coordination, and post-partum services. We utilized routine administrative data collected on each maternity patient in local health departments of the study area. Standardized reports generated through the State's health services information system (HSIS) provided valuable in-depth data on intensity of care coordination, continuity of care indicators, as well as use of support services such as transportation. Additionally, we relied on much of the data and information collected as part of the Baseline Needs Assessment conducted as part of the Phase I Planning Grant in 1999-2000.

To assess/track BLP program activities, special forms were developed to track all outreach and referral activities and were used by each CHA, the two Network Liaisons, and the Regional Manager. Daily log sheets were tallied on a monthly basis and summarized onto Monthly Contact and Referral Form (Attachment B). The forms were forwarded to the evaluation office and entered into an Excel spreadsheet. In 2003, the data reporting process shifted and information was sent to the data coordinator in Raleigh for entry and file creation, and final files were sent to the evaluation team at UNC Sheps Center for summary and analysis.

To assess participant (consumer) level information vital records including birth and death certificate data are merged with Medicaid and selected health department variables on an annual basis by the State into a file locally known as the Baby Love file. The evaluation team obtained Baby Love files for 1996 through 1999 (baseline) for all births in the study and comparison counties, and for the 2001 through 2004 program period. This represents the core data to assess program impact on infant morbidity and mortality — the goal of this program. We have the detailed birth files for 2001-2003 which provide information on risk factors, service utilization and birth outcomes. However, the birth files do not have any information about Medicaid coverage or infant death, and thus have only descriptive information and no outcome or final evaluation information for the true study period. The final data will not be available for an accurate assessment of program impact until the 2004 birth cohort has had a full 12 months for the potential of mortality and for completed Medicaid claims to be processed. The expected date for availability is November 2006. Data shown are for the pre-project period and early program period. Fortunately, the HSIS data collected through local health departments are available more rapidly, and we have data through 2005 that include information on use of maternity care coordination, selected demographic and risk factors, as well as key birth outcomes.

Section III. Evaluation Findings

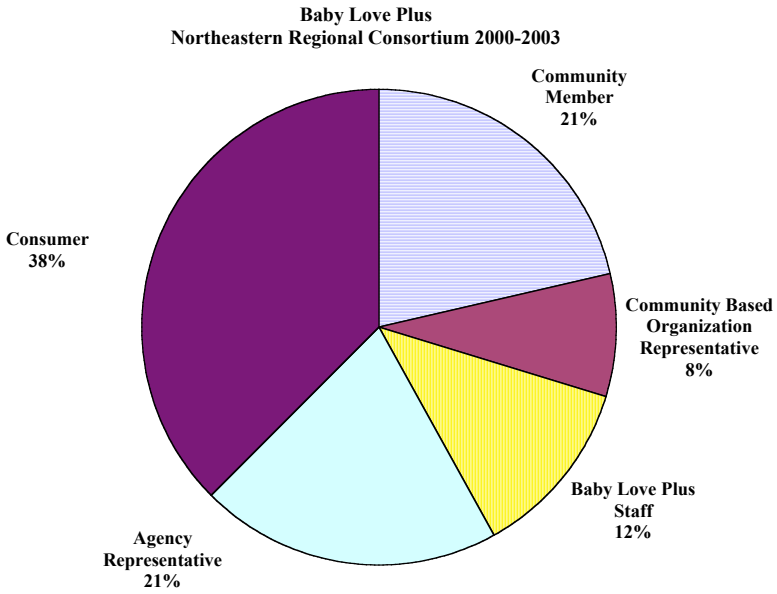
As described above, the evaluation was designed to assess the effectiveness of the BLP-Northeastern program in realizing four main objectives and reaching the overall goal of reducing infant mortality and morbidity in the project area. Evaluation strategies and data were collected and compiled across the four levels of a) community, b) systems of care, c) program, and d) individual participant levels as discussed below. Results are presented for each level assessed in the evaluation. In some instances, findings were relevant across more than one level; for example, some of the community survey data included feedback from local partner agencies that also informed us about systems of care. In these cases, findings are included in each section that applied.

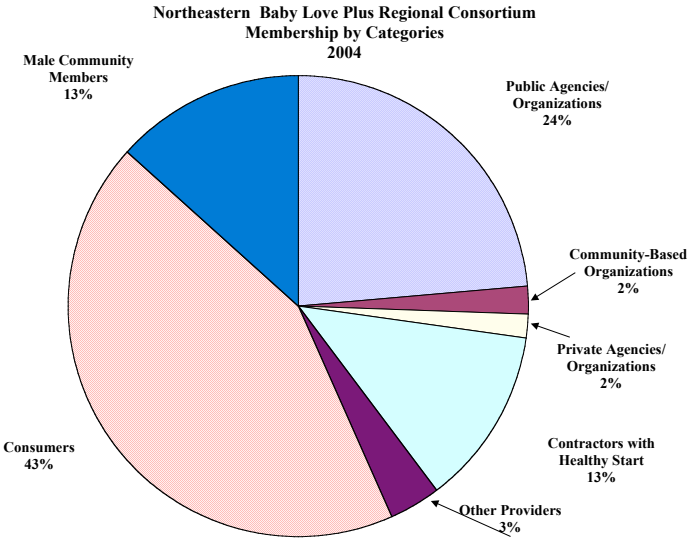
A. Community Level: *Overview of Consortium: membership, participation, representativeness, trainings held, feedback from surveys*

One of the key components of community-level efforts of the NC BLP Program was and continues to be the existence and work of the BLP Regional Consortium. The counties of the Northeastern Region did not have existing coalitions focused on infant mortality reduction or improving birth outcomes at baseline (prior to the *BLP* program). In 1999-2000, no area-wide Consortium existed. The Healthy Start *Baby Love Plus* efforts added the development of a regional consortium that covered the five project counties, and focused on increasing consumer

involvement in the prevention of infant mortality. The Regional Consortium was started in 1999, with regular meetings and ad-hoc sub-committee meetings.

Since its inception, the BLP-Northeastern Regional Consortium has grown in popularity and developed a regular group of members who participate in activities. There was wide interest in participating from the start with over 50 registered members in the first year, and an average of 45 members attending half (or more) of all meetings. By 2004, the Consortium had grown to a group membership of 175, with 102 of these being active members (attending half or more of all RC meetings, committee meetings, or Consortium-sponsored events). There is a regular core of 19 dedicated members who attend every meeting and who are active on sub-committees and in leadership positions (guiding the LHSAP process, for example).





Considerable effort has gone into increasing community and consumer involvement in the Regional Consortium; we are well on the way to the goal of 51% consumer and community member participation. At the end of the project period, 59 % of the overall Regional Consortium membership was either consumers (38%) or other community members (21%). One response to increasing consumer involvement was an effort to create a special staff position dedicated to working with consumers and increasing their involvement. This position was filled (after the project period for this report) in mid-2005 and work is actively underway. Another goal was to ensure that the Consortium composition was representative of the population it was serving with regard to race and ethnicity.

This goal was far exceeded. While the proportion of births in the study area is 52% African American or American Indian (1999-2005) and on average 80% of health department maternity clients are African American or American Indian (2001-2004), the proportion of Consortium

members who are African American or American Indian at the end of the project period was 92%.

Several community surveys have been conducted during the project period to assess feedback from consumers, providers, and community partners. All members of the Northeastern Regional Consortium were interviewed as part of the *Baby Love Plus* Program's Community Survey, completed in 2000. Of this total group, 33 % were Agency representatives or health care providers, 19% were consumers (including male partners) or community representatives, 12% were Healthy Start staff members, 16% were representatives of CBOs within the Region, and 20% were from other public agencies or organizations such as the local DSS or schools. Seventy-nine percent were African American and all but four were women. Topics included knowledge and awareness of infant mortality disparity issues and related risk factors, beliefs about seriousness and causes of these factors, and feedback about the BLP program and effectiveness of perinatal services in the Region. Subsequently in 2002, 69 consumers from public and private maternity clinics from across the Region were interviewed post-partum. They were asked to give feedback about their use of prenatal and post-partum services, including MCC and family planning. Additionally, they were asked about pregnancy intendedness, experiences related to stress and /or family violence, and to rate the quality of services received and level of satisfaction with their care. Detailed results are included below under systems of care and findings related to program services.

In 2003-04, a special grants program focusing on strengthening systems of care to address family violence during and around the time of pregnancy was implemented through the BLP Consortium and local health departments. Toward the end of the grant period, a "systems survey" was completed where local shelter staff, public health administrators, clinic managers, and community non-profit representatives were interviewed to determine improvements in the systems of care addressing family violence during the time period of the grant. Results were informative for many aspects of the systems of care in place to serve women of reproductive age and their families.

While the Consortium was very active during the 2000-2004 grants period, it did not have any formal activity dubbed as a "local action plan". The Phase I Planning Grant preceding this project period, and the needs assessment and program evaluation data that were actively used by the Consortium for setting goals and reviewing progress toward program objectives, served in the place of having a formal "action plan". However, beginning in 2005, at the end of the family violence grant, the Consortium's *County Action Subcommittee* took on a more formal role of requesting and reviewing program data and regional trends. Their intent was to determine if there were gaps that should be addressed in the broader perinatal systems of care within the Region, and most prudent strategies for addressing gaps. Our Year 1 (2005) continuation report covers the work of this group in more detail.

Key Results from Consortium and Consumer surveys about community-level issues: Knowledge, awareness, perceptions of infant mortality, BLP program existence, work of the BLP Regional Consortium, and feedback about prenatal and MCC services, including new services to address family violence.

There is a sense of common purpose across all three groups (consumer, agency representatives, community members, and staff) that both the goal and mission of the BLP program are consistently reported as addressing infant mortality (IM) and providing information and services to improve birth outcomes. Almost all members mentioned some aspect of supporting families in-need, especially those who had experience with infant loss or poor birth outcomes. Almost all understand that the *Plus* in *BLP* relates to enhanced services, outreach into the community, providing transportation, extending care beyond the medical setting, and developing a Regional Consortium.

Additionally, almost all the Consortium members suggested that there should be more consumer involvement in the Consortium. Suggestions included:

- "Meet where the consumers are."
- "Have an awareness month during March."
- "Seek some way to draw more people. Maybe move it back to Roanoke Rapids."
- "Do some audience participation activities (Warm-up) something to make it fun and make it spread by word of mouth."
- "Move the meeting back to lunchtime. Have different speakers to do mini-sessions over the noon hour."
- "Give the consumers more than a meal and gas mileage, some people have to drive a distances to be bored for one hour. It's not worth it for some people."
- "Get members more motivated, active, and involved and encourage members to invite new members."

Key Finding: Impact of BLP Consortium and Knowledge of the BLP program

Overall, Consortium members are positive about the chances for success of the *Baby Love Plus* Program; the majority (67%) think it is likely that the BLP Consortium will have a positive impact on the community. Consumers who know of the Consortium say they feel they have at least "some" or "a lot" of input into the Consortium, however there was 20% who felt they had no input. Although many consumers do not know details of the program, most know that there is assistance available to them to get care and where they can go to get help (HD Baby Love program). About 25% of consumers associate the BLP program with help accessing maternity services or finding where to go for care (transportation or outreach and referral).

Key Finding: Community Level Knowledge and Awareness of Infant Mortality

The majority (62.3%) of Consortium and consumer members consider infant mortality a "very serious issue" even when compared with other social and health problems. Knowledge about SIDS is very high and this was one of the most frequently identified mass media messages that people remembered seeing or hearing. Almost all (91%) consumers surveyed knew the importance of "back to sleep, tummy to play" positioning of babies. Very few consumers (<16 %) know about racial disparities or the excessively high levels of infant mortality in their region relative to the State. Over 85% said they were "not sure" how their rates compared to the rest of the State, or erroneously thought that their rates were better than the state average when in fact they are some of the worst in the State. Half of consumer respondents were not aware of low birth weight or prematurity as major factors in poor birth outcomes.

Sometimes when we mention about the babies that are dying, infant mortality part of it, and tell them that it's our purpose is to go out and target the African American community and a lot of people don't realize that so many black babies are dying more so than white babies.

I didn't know anything about it (in response to the Moderator's question regarding the general African American public's knowledge of the high incidence of infant mortality) *until I started working for the program.*

It's both (attitude and what you're saying). *A lot of people are astounded that black babies are dying three-to-one. When you tell the average person that . . . nobody is aware of that, nobody. If you tell anybody, I mean from the poorest to the richest person, black babies are dying three-to-one in this community they are like, shocked.*

Being honest, before I got into Baby Love Plus I didn't know that many black babies was dying.

B. Systems Level: *Overview of Perinatal Systems of Care: use of prenatal care and ancillary services, suggestions for improvement, feedback about maternity care coordination and its efficacy.*

Of the 2,736 births at baseline in the study area (2000), 668 (24.4%) were to women who received maternity care coordination. This represents 69.4% of all the HD maternity clients in the Region at baseline. As the MCC program is administered from the local HD, we analyzed data for this population to track trends related to the efficacy of MCC care.

During the study period, 4,526 women in MCC received a home visit either prenatally or in the post-partum period. Of those enrolled, each year between 55% and 65% deliver and on average this represents between 618 and 678 women. Very few of these clients have no prenatal care: nine of 668 in 2000 (1.3%) and three of 678 (0.4%) in 2003. During the program period, there was close to a five percent improvement in proportion of pregnant participants who had a prenatal care visit in the first trimester (from 57.8% in 2000 to 60.6% in 2003.). There was a slight improvement from baseline to end of project period in early entry into prenatal care for program participants. Comparable rates for the general maternity population in the area did not increase as much (81.5% in 2000 to 83.1% in 2004), suggesting some success for BLP efforts. While this shows improvement, there is still great need for increasing these rates for the higher risk women that BLP strives to reach. In terms of adequacy of care, using Kotelchuck Index's "adequate/adequate plus" categories, about two-thirds of BLP participants (65% average) are receiving this level of care. MCC assists with a range of needs from nutrition counseling and food assistance to housing, job training, school enrollment, employment, childcare and transportation. As a result of the pre-program (1999-2000) planning grant needs assessment showing that transportation was a major barrier in this rural region of the State, each county instituted new transportation services for their maternity clients. During the project period, 830 women were provided with transportation services which, as a measure of effectiveness of linkages across systems of care, indicated better coordination and follow up between agencies

working within the perinatal care system. In all three of the NC Baby Love Plus Regions, this an area that the Consortium's Action Plan committee's have addressed through working to improve linkages both within programs at the local health departments as well as externally with local neighborhood clinics and special community programs, such as family violence or fatherhood initiatives. One other measure of these efforts has been following up on missed appointments, especially for family planning visits. The following key points are summarized from feedback from consumers interviewed in maternity and postpartum/well-child clinics.

Key Finding: Knowledge, Use, and Quality of Prenatal Care
Most all (98.6%) of the women interviewed had some prenatal care and most say they started going for PNC in the first six weeks. In fact, 94% of our consumer respondents said they had received early PNC. While a significant proportion of the women interviewed received prenatal services through their local health departments (45.6%), a sizeable proportion (44.1%) went to a private physician's office for their care. Close to seven percent went to a rural health center and the remaining went to a hospital outpatient clinic. There is a fairly good understanding and awareness of folic acid and the importance of taking a multivitamin before and during pregnancy (however only 50.7% of respondents correctly answered this question). Knowledge about SIDS is very high and this was one of the most frequently identified mass media messages that people remember seeing or hearing. Approximately 91% of respondents correctly answered the question about positioning a baby on its back. This is higher than the State average of 76.7% (1999 PRAMs survey).

Key Finding: Quality of prenatal care services: (levels of respect experienced, issues of discrimination, clinical care experience, information received, gender and race preferences of provider, ease of keeping appointments)

Respondents were asked for their feedback on the quality of care they received during their prenatal visits. They were asked specifically about which topics were covered when they met with their providers, how comfortable they felt, and whether they had adequate time with their providers; their thoughts about the quality of the facility in terms of adequacy of equipment and basic cleanliness; whether they perceived issues of discrimination either in terms of ability to pay or other factors like race/ethnicity; and how important features like gender and race/ethnicity of their providers are in determining the quality of their care. While there were several notable concerns, most clients report very good experiences with the care they are receiving, and give the system good marks.

Key Finding: Level of respect shown by providers: Consumers consistently rated the level of respect shown to them by their maternity providers as "excellent" or "good." Specifically,

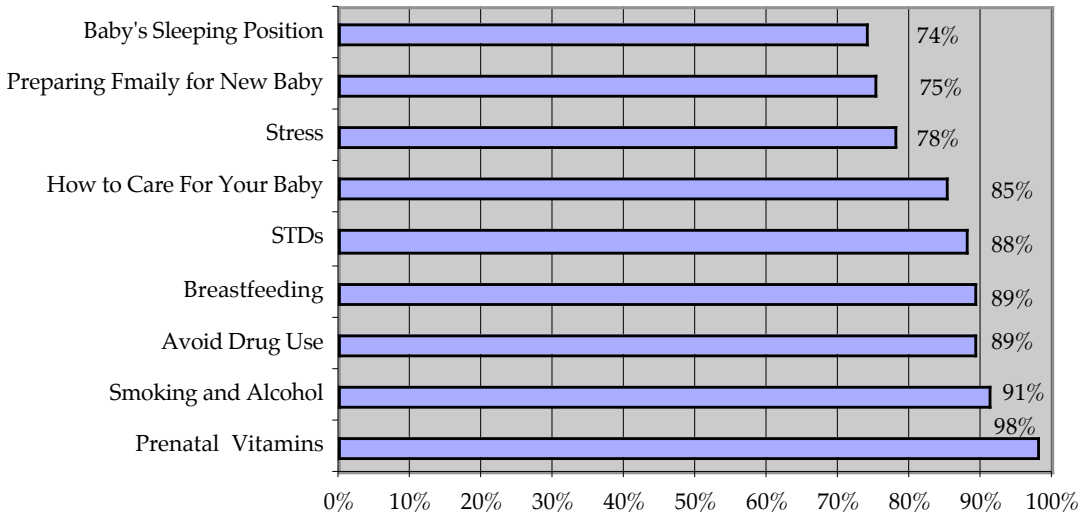
- They rated doctors, midwives, and nurses as "excellent" (58%) of the time, while doctors and midwives were also rated as "good" (31%), and nurses (34%) of the time. Several respondents mentioned differences between providers with some showing a much higher level of care and respect than others.
- There do not appear to be differences by type of clinic or across counties, however when respondents mentioned feeling a lack of respect, it was often more with the receptionists than the medical staff (responses range from the over 90% who felt they were treated with respect

by their provider to the [lower] 85% ("excellent" or "good" responses) who felt respect shown by receptionists).

Key Finding: Issues of discrimination (race, financial status): Although a majority of respondents (54%) said race was not a factor at all in their receiving services, over 16% said "fair" or "poor" when asked to rate whether race was an issue in receiving care. Similarly, just under the majority (49%) thought the quality of medical care did not change regardless of how patients paid for their medical care. Financial status was cited, however, as a factor in several cases (18% rated this issue as "fair" or "poor"). This may be a misperception on the part of consumers as they reported that they did not go because they did not have Medicaid and thought they would be required to contribute a co-pay that they did not have.

Key Finding: Quality and Content of Clinical Services: The following graph depicts the topics covered during prenatal care and the percentage of women who received information about each subject. While the general coverage of topics is very comprehensive with at least 74% of the respondents mentioning each topic being covered, note that stress, preparing for a new baby and sleep position were mentioned the least (or not remembered as being covered as often).

Proportion of Clients Who Said the Following Topics Were Covered in PNC



Key Finding: Barriers to Prenatal Care and Recommendations for Enhancing Services
What services would make it easier to use PNC? Consumers were asked questions in two different areas of the survey that addressed need for additional services. The first question (Survey question # 25) asked was "Would any of the following services have made it easier to keep your prenatal care appointment? Of the choices listed, the only categories where a *majority* of the respondents said "yes" were:

- The question on "home visits": 61% of respondents said home visits would make it easier to use PNC; *and*
- The question on transportation: 61% said "yes";
- Twenty-six percent said childcare would help, while an equal percent said "no" to child care.

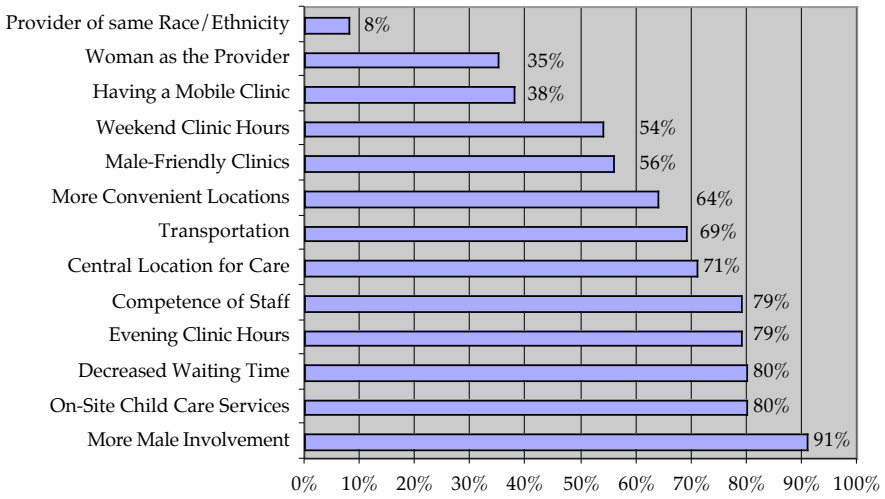
Key Finding: Recommendations to improve use of prenatal care services
The second question that related to what would be necessary to improve prenatal services was: "How important is each of the following for improving these services? Is each very important, somewhat important, or not very important?"

The issues most often mentioned as being "very important" were:

- having more male involvement (91% said this issue was "very important")
- decreasing waiting times in the clinics (80%)
- having more on-site child care (80%)
- having evening or extended clinic hours (79%)
- assuring staff competence (79%)
- having central location for care (79%)
- improving transportation (69%).

Also interesting were topics mentioned as NOT being as important: the provider's race or ethnicity or gender, weekend clinics or mobile van, and more convenient locations were reported as being less important.

Proportion of Consumers Reporting the Following as "Very Important" for Improving Prenatal Care Services



Male Involvement: Ninety-one percent of all respondents thought that more male involvement was very important in improving prenatal services. Male involvement is a big issue that many respondents, including Consortium members and clinic patients, mentioned as needing a lot more emphasis. This is an area that needs more follow up to determine the best approach and what exactly should or could be done.

Waiting Time in Clinic: Perhaps, the next most pressing issue after "male involvement" was waiting time in the clinic, with 80% of consumers reporting "decreased waiting time in the

clinic" as "very important" (tied with Child Care, see below). Consortium members also mentioned the problem of long waits in the clinic. Both Providers and Healthy Start staff specifically mentioned the need for less time waiting for an appointment and for shorter and better waiting times once the client arrived at the site. The issue also seems to be tied to the need for more flexible clinic hours. Seventy-nine percent of clients reported that "evening clinic hours" were "very important" and Consortium respondents also mentioned the need for "flexible clinic hours" and/or "evening hours" and/or "longer clinic hours."

Child Care**:** On-site childcare services were listed as "very important" by 80% of the respondents. Currently, 27% of the respondents brought their children with them to their clinic appointment while another 23% had family or friends look after them.

Transportation: In numerous different questions about barriers to PNC, in ways to improve outreach, in how MCCs can be more effective, and in ways to enhance clinical services, consumers tell us that transportation is a key factor in getting their care, even in an urban area where there is public transportation. Transportation is one of the main barriers to accessing care in the Northeastern Region. Over a third of the respondents in the community survey state that they travel 16 to over 30 miles to reach their prenatal appointment. While 38% say they have their own car, another 48% rely on public transportation, a taxi, or "other" (usually a van or public assistance vehicle). Sixty-nine percent of Northeastern respondents mention improved transportation as very important in improving clinical services.

C1. Program Level: Maternity Care Coordination (MCC)

Nearly all of the clients (76%) remember being offered the services of a MCC. Of the sixty-one respondents who remember being offered an MCC, 50 (82%) accepted the service. The few that did not choose a MCC stated that it was because they did not see the need, had family support, or were very familiar with the system already and did not think it would help them further.

Key Finding: Feedback about Maternity Care Coordination (MCC) and its efficacy.
MCC Help: Finding out about WIC (100% of respondents) was the number one item mentioned. Also, enrolling in Medicaid (80%) and help with transportation (88%) were very common. Other areas mentioned were finding a pediatrician, making appointments, help with housing, finding maternity clothes, where to get a car seat, how to enroll in Baby Bucks, resolving problems with spouses, help with employment, and general support. Almost all respondents who had a MCC remember talking about WIC, Medicaid, transportation, and childcare.
Satisfaction with a MCC: The vast majority said they were either very (78%) or somewhat satisfied (12%) even if they reported that they did not get anything from the MCC that they would not have had without them. In many cases having a MCC made a difference in both the prenatal period as well as for subsequent care. For a significant group of women, their MCC is a confidant, who helps them negotiate the system and make hard decisions. Many suggested the need to expand their time with the MCC beyond the 60-day post-partum coverage.

Barriers to receiving MCC service: There appear to be very few and are specific to individuals. But there were several suggestions from respondents when asked what could be done to improve

MCC services. The first suggestion was the need to be able to follow mothers longer (up to two years post-partum) to be able to establish trust, build the relationship with the family, and empower the client. Other comments were that there are not enough MCCs, a lack of commitment on the part of some of the MCC workers, and the need for better training of the current cadre of MCCs.

Provider feedback on systems of care

Maternity Health Services: From the original survey of Provider-members of the Consortium, only one rated the quality of health services as "poor or "very poor" (in answer to the question of "how would you rate the following areas relative to the quality of health care services?") The items that she identified were: the "level of comfort the doctors or providers provide; the level of concern shown to clients by nurses;" and "whether the care provided is the same for all clients, no matter what race or ethnicity is and/or no matter how services are paid."

Barriers to Care: What factors did providers say stand in the way of women getting adequate prenatal care? Every respondent thought transportation was a barrier while other barriers listed in order of frequency include:

- Knowledge of the benefits of prenatal care for all women
- Child care problems
- Time due to other commitments/time off from work
- Lack of money
- Trying to keep their pregnancy secret/ Undecided about continuing the pregnancy
- Difficulty finding a medical provider they like
- Hard time scheduling appointments

What did respondents recommend to improve prenatal care services for women in their counties? The most frequent comments made had to do with the transportation issue and location of clinics. Other recommendations made by members related to sensitivity and compassion of providers, cost, and educational information being made available in the community.

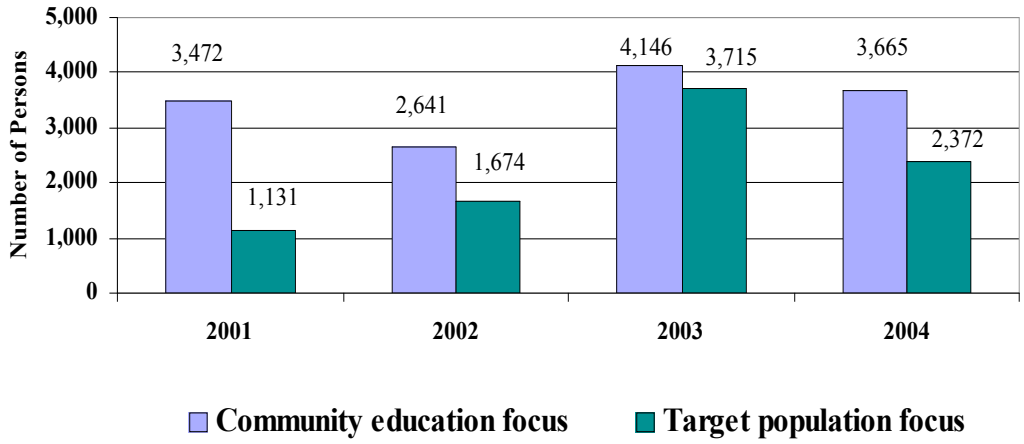
C2. Program Level**:** Outreach and Referral Services

Outreach: The Northeastern *Baby Love Plus* intervention counties hired and trained Community Health Advocates (CHAs) between January and July of 2001. The CHAs were fully operational by August in all counties and data are shown for the period January 2001 through December 2004. The main outreach activities were directed towards individuals in the targeted areas, but CHAs also spent substantial time contacting people in groups, such as Health Fairs, Festivals, and baby showers. Individual contacts are defined as persons with whom CHAs/liaisons have personal level communication, including information about *Baby Love Plus* services. Dropping off literature at someone's doorstep or handing out flyers at health fairs does not constitute an individual contact.

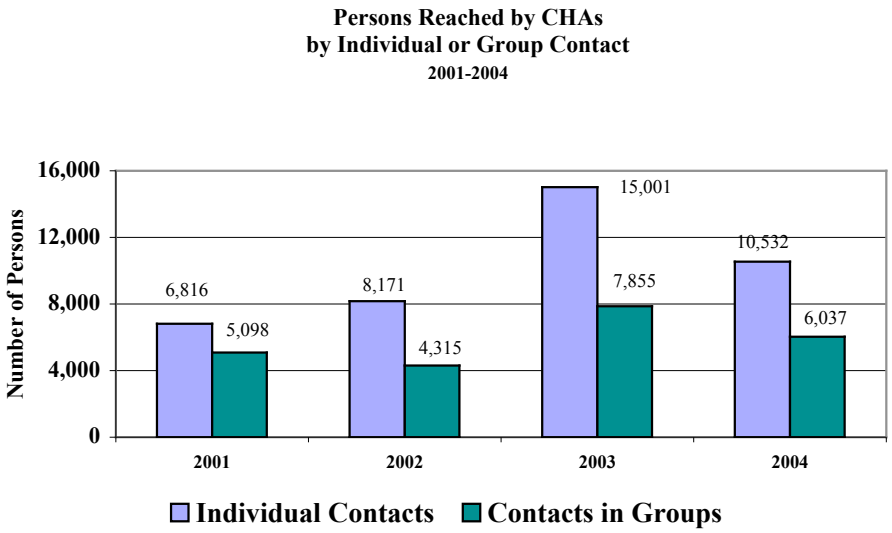
A group contact was an organized or pre-planned event of more than one person where general information about *BLP* is given. A health fair or festival-type event, for example, was considered a group activity. Outreach to groups was divided into two focus areas: groups such as local businesses, medical offices, churches, or community events such as health fairs, or house

parties, baby showers, DSS office waiting rooms or locales where the focus was more directly on women of reproductive age in our target neighborhoods. When recording the number of group contacts, *BLP* staff tracked the number of people who stopped by a table, or people who picked up a brochure at a health fair. They did not count the total number of people attending a health fair, or neighborhood-wide event.

CHA Outreach in Group Settings by Focus of Group
2001-2004



During the 2001-2004 project period, the staff made 13,924 contacts through community group settings and another 8,892 contacts through targeted group settings, for a total of 22,816 contacts in the community through group meetings. The total number of people reached through *Baby Love Plus* outreach efforts in this time period was 63,825 individuals or an average of about 1,330 people per month. Note that these numbers are not unduplicated, and it is possible that the same person who was reached through a group session may have also been contacted individually at a later date. The overall effort in terms of numbers of people reached by BLP Northeastern staff is impressive, representing much work across many community groups, settings, and events. Individual level contacts are the main way that CHAs work in their communities to reach potential clients. However, a significant number of people are reached through group events — almost half to a third again as many contacts every year.



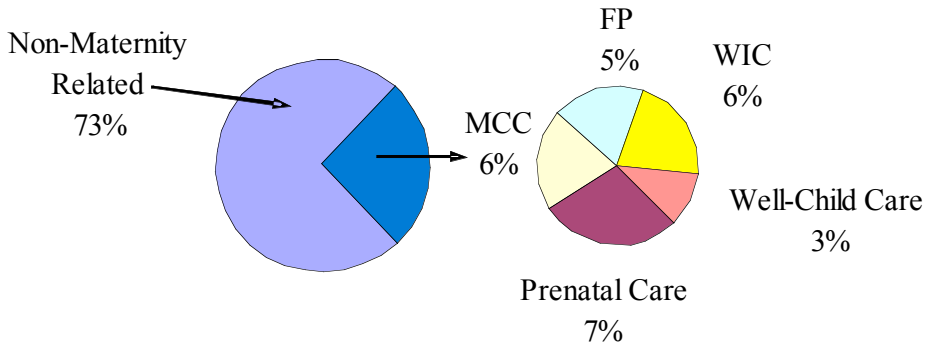
Over time, both the number of individual and group contacts has increased, despite the staff numbers remaining constant. A shift in the focus of the program away from a general community approach to a more targeted and intensive approach has encouraged CHAs to provide outreach to women of reproductive age likely to have a need for perinatal-related referral. The numbers reached through groups that have a general community base versus groups whose focus is on the program's target population — social gatherings such as baby showers, home parties, and ladies church functions is in line with the revised program goals. While the proportion of individuals contacted who are reached through targeted, social gatherings is still only a fraction of the overall outreach in group settings (1,505 of 22,816), their strategies and approaches are gaining popularity and resulting in higher numbers of referrals into services. In addition to conducting outreach through group meetings, the CHAs also concentrated great efforts around outreach to individual women who would be potential clients. Over the 2001 to 2004 project period, as shown in the graph above, there was a shift in targeting efforts from broader community wide or group events to more focused, one-on-one individual contacts. By the end of this project period, CHAs had increased their individual-level contacts by 50% from 6,816 to 10,532 and in the year prior (2003), when staff positions were fully filled, the effort had more than doubled from the baseline years to later years. The real key in terms of outreach effectiveness is whether a contact results in a successful referral, i.e. one that identifies a new client who will enroll as a program participant.

Referral for Services: Of the total 40,520 number of individual (primary) contacts made between 2001 and 2004 across the five-county region, 4,422 (6.0%) were referred for some kind of follow-up service. This represents over 1,000 referrals per year. As the emphasis of BLP outreach is to identify high-risk women and refer them to appropriate care, this is potentially quite positive, however the *proportion* of only six percent is quite low and has been an area of emphasis and concern. Referrals are not limited to pregnant women, but to post-partum women and their newborns as well. As is shown in the graph above, the proportion of contacts made by CHAs in general community education far outweighs that of more-targeted individual-level intensive outreach. This already has begun being to shift in the new program period and it is

hoped that the results will show a reversal in trends in the near future, where outreach results in more targeted contacts and a larger proportion of referrals into maternity-related care.

The breakdown for referrals made is shown below. The group of individuals reached through direct (individual not group) contact with CHAs that were given a referral was only 11.7%, and even though this *number* was fairly high (6,662), only a small proportion of these referrals was for a service related to perinatal care — either prenatal care, maternity care coordination, WIC, or family planning. Only seven percent of all the 6,662 referrals were for prenatal care, and only six percent were made to Maternity Care Coordination. Other referral needs of clients include Department of Social Services (DSS, 3%), Family Planning (5%), Well-Child Care/ Immunizations (3%), and WIC (6%). Some of the needs included in the "other" slice of the pie below include housing, crisis control, day care, and transportation. Over eighty-eight percent of primary contacts (i.e., outreach to WRA in the target communities) were given no referral, indicating the need for more and better targeting of outreach efforts.

Reasons for Referrals by CHAs
Maternity and Non-Maternity Related
N=6,662
2001-2004



Memory of Outreach Workers in Neighborhoods: In the early community surveys, there were some respondents from the consumer portion (10.1%) who remembered seeing a *BLP* CHA in their neighborhood (house party) or having a *BLP* CHA visit them. This was excellent considering consumers were initially surveyed after only four months of outreach activities. Subsequent surveys in the region are now underway to gauge consumer knowledge, awareness, and program interests.

Key Findings: Recommendations for Improving Outreach

- Focus less on quantity of contacts and concentrate more on quality of the interaction, spending time to become familiar with a clients situation and possible needs. Gather enough information to make a good determination of needs and appropriate referrals for service.

- Realize that the barriers people mention most often are ones that are most difficult to address such as finding the hard to reach families, reducing unrealistic caseloads, and having better coordination with referral agencies to know if families have been able to access the services they need. Nevertheless, they are the ones that warrant persistent effort.

Participant (Individual) Level

Demographic Trends and Participant Profiles

In the Northeastern study region, there have been 12,776 births over the four-year study period, an average of about 3,200 births a year based on birth certificate data. Just over half of these births are born to African American women and about 2% are born to American Indian families in the region. While the proportion of births that are to Hispanic women is very small, it has been steadily growing: from 3.4% in 2000, to 4.6% in 2001, to 5.1% in 2002, 6.2% in 2003, and 6.9 % in 2004. Close to 40% of the area's births are to women who were clients of their local health department. While the proportion of births that are to Hispanic women has doubled in the period from the start of the project to 2004 from 3.4% to 6.9%, these births still represent a very small proportion and number of the region's maternity clients. Local Health Department clients compared with the general population are more likely to be black (79 % versus 54%), less likely to be Hispanic (4% versus 9%), more likely to be less educated (65% versus 38%), and unmarried (84% versus 38%). The number of Hispanic participants (i.e., maternity clients enrolled in Baby Love) has declined over the project period (despite slight increases in the general maternity population of Hispanics) from 3.5% in 2000 to 1.8% in 2003. The BLP evaluation focused analyses on participants of the BLP program who were by definition maternity clients at their local health department or public health clinic and who were enrolled in the State's Medicaid for Pregnant Women (MPW) case management services (Baby Love). Over the four-year project period, there were declining numbers of women enrolled in Baby Love — from 1175 in 2000 to 1086 in 2003 and further to 917 in 2004. The proportion of births to teens (<20 yrs) and rates of poverty have remained constant over the project period, with 381 of 1175 (32.4%) being teen mothers in 2000 and 305 of 917 in 2004 (33.3%) and poverty levels (% families at or below 100% FPL) being 529 of the 1175 enrolled MCC women in 2000 and 489 of 1086 in 2003 (both 45%).

Risk Factors: *poverty, smoking, RTIs, anemia, diabetes, intendedness*

As outlined in the program narrative, the northeastern project region is characterized by high rates of poverty, with close to a quarter (23.9%) of under18 year olds living in families with incomes below the Federal Poverty Level. The program participants who are receiving services through their local public health departments have higher rates of poverty than the general population. HSIS data from 2002-2003 (mid-way through the project period) indicate that 33.7% of maternity clients are at or below the Federal Poverty Level and between 60% and 85% of births in the region are paid for by Medicaid (compared with 46% for the State overall).

Not surprisingly, women in the Region have higher prevalence of risk factors compared with other women in the State. Smoking rates are high at 15% on average for the Region and considerably higher in sub-groups such as among American Indian women; reproductive tract infections (Chlamydia and gonorrhea) are as high as 40 and 50 per 10,000 often double the State average in many of the Region's counties; and the proportion of women who have a history of diabetes, hypertension, or anemia prior to becoming pregnant is between one third and one half

in many areas of the Region. The ratio of abortions to live births is as high as one abortion for every three to four births for Minority women and on average about one in ten for White women in the Region — with between a quarter to a third of all pregnancies to Minority women in the Region ending in abortion, and about 10% of pregnancies to White women being aborted — clear measures of high unintended pregnancy rates.

Table 6
Northeast Local Health System Action Plan:
Risk Factors for Pregnancy
2003

Risk Factor	Gates	Halifax	Hertford	Nash	North-ampton	North Carolina	Definitions
Total Births	105	739	295	1150	249	**118,292**	Resident Births
Minority (%)	39.0%	67.0%	76.0%	37.0%	63.0%	**27.0%**	Mother's Self-report
Unmarried (%)	W 31.2% NW 63.4%	W 37.7% NW 77.7%	W 35.2% NW 73.6%	W 27.6% NW72.4%	W 21.9% NW 76.0%	**W 26.0% NW 60.4%**	Mother's Self-report
Medicaid (%)	60.0%	81.0%	84.4%	62.0%	71.1%	**46.0%**	Birth Paid by Medicaid
Eligibles Enrolled In MCC (%)	52.3%	46.2%	63.4%	51.8%	65.0%	**48.0%**	% of Medicaid eligibles
Late/No PNC	12.3%	16.7%	16.4%	22.1%	13.9%	**15.5%**	No PNC/After 3rd month
Low Birth Weight (%)	12.3%	12.3%	15.0%	9.3%	13.8%	**9.0%**	Wt < 5.5 lbs.
Very Low Birth Weight	W 0.1% NW 0.0	W 0.5% NW 2.8%	W 2.8% NW 3.1%	W1.0% NW 3.0%	W 2.2% NW 7.0%	**All 1.8%**	Wt < 3.3lbs
Teen Births	18.0%	20.0%	20.0%	14.0%	18.0%	**20.4%**	Births<19yrs
Inadequate Weight Gain	15.2%	14.3%	20.3%	16.0%	14.1%	**12.2%**	Under 19 lbs
Mother Smoked	12.6%	17.4%	6.4%	14.6%	15.3%	**All 13.3%**	Birth Certificate
Anemia, Diabetes, or Hypertension	W 15.6% NW 9.7%	W 26.6% NW 36.3%	W 5.6% NW 8.9%	W 45.0% NW55.0%	W 22.0% NW 25.3%	**All 30.0%**	History of Pre-pregnancy
Chlamydia	22.8	53.9	38.0	35.8	52.1	**28.5**	Cases per 10,000
Gonorrhea	12.3	46.6	26.6	33.4	43.5	**20.7**	Cases per 10,000
SBI	12.1%	11.8%	11.4%	13.1%	10.3%	**12.1%**	< 6 months birth to conception
Unintended Pregnancy (Abortion ratio)	W 1:16 NW 1:7	W 1:9 NW 1:4	W 1:5 NW 1:4	W 1:10 NW 1:3	W 1:11 NW 1:3	**W 1:14 NW 1:4**	Abortions / Live Births
Abortion Fraction	W 6.3% NW 14.6%	W 15.6% NW 25.1%	W 19.7% NW 25.4%	W 10.3% NW 35%	W 8.8% NW 19.6%	**W 13.8 NW 42.1**	Abortions / Pregnancies
Induced Abortion #	W 4 NW 6	W 38 NW 124	W 14 NW 57	W 74 NW 150	W 8 NW 31	**W 11,941 NW 13,471**	Total reported 2003

The profile of general births in the Region and births to program participants is one of high risk, with many of the risks being those related to general lifestyle, and that exist prior to the time of pregnancy such as anemia, diabetes, hypertension and reproductive tract infections. Despite the fact that maternity services are available at little or no cost to any pregnant resident of the Region, still many families face multiple stressors that go beyond accessing health care — and that affect the ability of families to make best use of services and programs that are available to them. A survey of clients who had recently delivered babies documented the high rates of stress

and factors often contributing to stress in their lives. Results are described below, and are considered some of our key findings.

Key Findings: Experiences related to stress and/or family violence

Stress is increasingly being recognized as a key risk factor for poor birth outcomes. Understanding the level and patterns of stressful life events is a basic step toward documenting and addressing these factors. Respondents in our 2002 consumer survey were asked about life events that may have caused stress or instability in their lives. Women were read a list of some things that may have happened in their lives during the 12 months before their child was born, as listed on the standard PRAMS survey. The following table lists the items asked and percents responding positive along with the comparable NC figures based on 1999 PRAMS data.

Table 7
Stressful Life Events Experienced During Pregnancy
NC PRAMS (1999) and BLP Northeast Consumer Surveys (2002)

	NC PRAMS Medicaid Respondents	BLP NEast Consumer Survey	% Difference: BLP vs. State Average
Job loss / self	15.9%	11.6%	(-) 27.0% less likely
Job loss /husb or partner	15.3%	21.7%	(+) 41.8% more likely
Couldn't pay bills	31.9%	24.6%	(-) 22.9% less likely
Argued w/ partner > usual	37.6%	46.4%	(+) 23.4% more likely
Husband or partner did not want pregnancy	13.3%	24.6%	(+) 85.0% more likely
Involved in a physical fight	9.3%	11.6%	(+) 24.7% more likely
Someone close had substance abuse problem	16.6%	15.9%	(-) 4.2% less likely
Husb/partner or I went to jail	7.6%	8.7%	(+) 14.5% more likely
Separated or divorced	15.0%	30.4%	(+) 103% more likely
Moved	40.6%	29.0%	(-) 28.6% less likely
Homeless	6.9%	1.5%	(-) 78.3% less likely
Family member hospitalized	29.0%	41.0%	(+) 41.4% more likely
Someone close died	23.6%	30.4%	(+) 28.8% more likely

[+] 1999 Pregnancy Risk Assessment Monitoring Survey of NC births (N=2400); Number of respondents Medicaid in 1999 = 893 of the 1780 total, or approximately 50% of the sample.

As is shown, women report experiencing many stressful life events during pregnancy, and for most of the indicators, are notably more likely than other pregnant Medicaid women in the State to report having these stress factors. These figures illustrate that many of the women in the Northeastern NC project area compared with the rest of the State, have significantly greater

challenges to assuring stability and security in their lives — almost a third moved at some point during pregnancy, were separated or divorced, experienced the death of someone close to them, and argued more than usual with their spouse or partner. Almost a quarter of the women report that their husband or partner did not want the pregnancy, and sizeable proportions mention problems with paying bills and job insecurities, being in a physical fight (almost 12% of the women), and having someone close to them with substance abuse problems..

When asked about experiences with physical abuse and partner violence, close to nine percent report that someone had pushed, hit, slapped, choked, or physically had hurt them in some way during their pregnancy — and husbands or partners were involved in one-third of these. Women report that prior to pregnancy 8.7% experienced some form of violence by either a husband or partner or anyone else. Comparable State figures are 11.4% for women experiencing any physical violence in the year prior to becoming pregnant and 7.8% of NC African America women report violence while pregnant.

Service Utilization: *Late/no PNC, early PNC, Kotelchuck Index, # medical visits in prenatal and post-partum periods, MCC, use of other related services (WIC and well-child care)*

As described above, in each program year there are on average 650 program participants who deliver their babies. Very few of these women have no prenatal care: nine of 668 (1.3%) in 2000 and three of 678 (0.4%) in 2003. While the program has shown an improvement in this area, the rates were very good at baseline and had very little room for positive change. In terms of timing and adequacy of prenatal care, there was a 4.8% improvement in the proportion of participants who had a prenatal visit in the first trimester of pregnancy (from 57.8% in 2000 to 60.6% in 2003) and a steady 65%, or about two-thirds of the group of program participants who had adequate/adequate plus (Kotelchuck) levels of service. A total of 73,822 prenatal medical visits were provided to participants over the four year period, averaging 18,456 per year or 16 per year per participant. While these figures show some improvement deserving of recognition, there is a need to persist in focusing efforts on bringing clients in early to care and helping them receive care according to the frequency and intensity recommended.

At this time, no clear trends have emerged for those in MCC receiving WIC because the overall percentage increases or decreases are generally small over time, and already at very high levels. The majority of MCC clients received WIC at baseline (97%), and continued to do so (96%) during the study period. On average 1100 participants received WIC each year. The majority of MCC infants received WIC at baseline (92%), and 90% received WIC during the study period. Clearer trends appear to be emerging for infants receiving well-child care. In the program counties, greater percentages of infants received well-child care at baseline for those receiving MCC. For the program counties, the percent of MCC infants receiving well child-care increased from a baseline level of (94.8%) to (95.6%) at the end of the project period and immunization rates have increased as well with 73% of children birth to two years of age being appropriately immunized in 2000 and 80% in 2004, representing a 8.75% increase.

Pregnancy Outcomes: *birth weight, neo-natal, post-neonatal and infant mortality.*

There are several success of note for the program's participants with regard to improvements in pregnancy outcomes over the project period. The percent of babies born weighing less than five and a half pounds decreased from 11.3 to 10.1 per 100 live births during the four-year program period. This represents a 10.6% improvement and is especially noteworthy when compared with the rates for the general population not enrolled in Baby Love during the same time period, which experienced an *increase* in low birth weigh rates from 10.2% in 2000 to 12.9% in 2003. The most dramatic reduction was for the percent of babies born to program participants at very low weight (less than three and a third pounds) showing a 37.5% improvement during the project period.

Infant mortality has also improved slightly, declining from 13.9 to 13.1 per 1000 live births from the beginning to the end of the program period. The decline was largely due to a relatively large reduction in neonatal mortality (death in the first twenty-eight days) rates from 9.3 to 6.5 per 1000 over the four years, which is impressive and represents a 30.1% improvement over time. The perinatal rates also showed a 7.1% improvement with rates declining from 19.7 in 2000 to 18.3 per 1000 in 2003. The pregnancy outcome rates for the MCC group are consistently better than those for the comparable general population (primarily African American), which supports the hypothesis that Baby Love and BLP services are likely to have a positive impact, despite the tendency for the higher risk women to be enrolled in MCC. Comparable low birth weight rates for example in the general population increased, rather than decreased, over the four-year period from 10.2% in 2000 to 12.9% in 2003. The infant death rates for the MCC clients at baseline and during the study period were 13.9 and 13.1 respectively as compared with those for the non-MCC African American women: 15.4 and 23.0 per 1000 live births — representing a considerable *worsening* rather than improvement as women who were program participants experienced.

In all, the efforts of the BLP-Northeastern program have exceeded their objectives on some indicators, are still working toward goals on other process and programmatic indicators, and for outcome indicators such as prematurity, low birth weight, and infant death, it is still too early to assess program actual impact for the defined study population. The program has achieved excellent levels of outreach and referral of high-risk women into care and has established an active, visible, and popular Community Consortium that serves to maintain high visibility for issues related to healthy birth outcomes and a voice for local community leaders and agencies to be heard in the process. Community capacity, responsibility for, and ownership of infant mortality reduction efforts have demonstrably increased during the project period. BLP outreach and referrals have resulted in appropriate and valued service provision, based on feedback from consumers and local providers. Birth outcomes in the project area appear to be improving, however final impact with comparable data for control counties cannot be determined until full data for program participants become available toward the end of 2006.

Section IV/V. Recommendations from Evaluation, Program Results, and Impact
Final recommendations are somewhat premature as outcome data for the study time period are not yet available. Full reports comparing pre- and post-intervention data as well as results compared with control counties will be possible as soon as the outcome data are complete and

made available. One major advantage of the NC program is the availability of a rich and extensive database that links vital records with Medicaid and health department data making possible a full analysis of program impact over time and compared with regions where no program existed. However, the drawback is that these data are part of the larger State reporting system, and as such are subject to the limitations imposed by staff shortages and the inevitable delays due to working with vital records. Final data for births to women included as participants from July 1999 through December 2004 will not be complete until mid-2006 and available for analysis in Fall of 2006. We continue to review program information and track trends in service delivery and outcomes for the study region, which are the results presented in and findings that are highlighted in this report. Any further extrapolation of the data or recommendations for policy or program changes would be unwarranted at this time.

The evaluation team has provided feedback to program managers regarding patterns of outreach and referral and use of facilitating services, where appropriate. These findings contributed to a number of decisions about the design and focus of program activities, most specifically a shift from a broad-based community approach to a more targeted, risk-based approach of case finding and referral for care. This new emphasis in program activities is reflected in the design of the current cycle of the Healthy Start *Baby Love Plus* project where CHAs are working as part of the MCC clinic team rather than as part of the health education and outreach team in most health departments. Data clearly indicate that outreach activities should be focused to match the known risk groups, rather than the community at large. The following recommendations are suggested based on preliminary findings.

Program Recommendations

Consortium: The BLP Consortium, over the course of the project period, evolved to become a large body of community members representing consumers, staff, and related health agencies. It was open to any and all who were interested in improving birth outcomes and getting the word out to the community about infant mortality issues. As such, the Consortium grew in size and has become somewhat unwieldy in that it is a large group with variable attendance. This has made decision-making and a task-oriented agenda more difficult. In order to maintain continuity and to assure effective representation across the key groups of stakeholders involved, it was recommended that a more effective approach would be to have a smaller membership, that was more focused, and task oriented. This group would essentially serve as a "steering committee" for the larger Consortium and consist of representatives of key stakeholders from the community. Another strategy to foster involvement across the large group but also maintain personal commitment was to activate sub-committee structures. This has been accomplished very successfully, with work-groups such as the County Action Committee taking a lead role in developing and implementing the local action plan (see Attachment and guiding related efforts.

Case Management and Outreach: Data from the early period of the program indicate there have been a large number of outreach contacts by BLP program staff with community groups and individuals, but a very small referral rate into specific perinatal services. Therefore the recommendation has been to better target outreach to primary contacts who would benefit from direct and immediate services, and to refocus group activities to specific groups of high-risk women rather than general public awareness based activities such as health fairs and community events. Data collection has been revised to reflect this recommended change. Outreach workers

are now required to follow up on referrals made and to determine, if clients are not able to make or keep appointments, the reasons for these problems.

Additionally, the program has planned a series of intensive and practical trainings for outreach workers on local data and risk factors most prevalent in the Northeastern program communities in order to (1) assure a clear and comprehensive understanding of the epidemiology of infant mortality; and (2) provide the tools to assure a broader and deeper understanding of these the risks such that the information is internalized by local staff. This is based on evaluation feedback that outreach workers and staff need to really believe and understand the data related to poor birth outcomes, and to be able to personalize the concern about short-term outcomes (mortality and prematurity) and longer-term consequences (disability, developmental delays, chronic illness) before they can convince others of their import, or before they can motivate at-risk individuals to take seriously the challenges and gravity of having a LBW, premature, or sickly child.

Policy Recommendations

Focused Prevention: There needs to continue to be a policy shift in the efforts of the BLP staff. The policy should redirect resources from a broad-based community-level approach that focuses primarily on the prenatal period to that of a case-by-case approach focusing on care and support during the interconceptional period. Broad-based, community-level outreach and awareness is good but not sufficient to realize an impact on the population of families at highest risk, and therefore unlikely to lead to reduction in basic indicators such as low birth weight and prematurity. Data show that the best predictors of these risks are previous history of poor outcomes, and that they are more likely to occur among African-American families living in specific low-income neighborhoods. The focus of current BLP activities concentrates on family care coordination after the 60-day MCC close-out for those families not already enrolled in CSC and who have clear risk factors. Intensive, individualized services by a LCSW over 24 months that identify and support needs across key domains of a woman's life is the model that is evolving in the new cycle of NC Healthy Start programs and that which is currently being tracked for success. This model will have only limited success however, unless staffing and management provide the program with the necessary resources and support. It will take time to shift emphasis among outreach workers from the community, public awareness approach to a more targeted case management approach where staff see themselves as part of a case management team, rather than as health education agents, working in parallel rather than in tandem with the local MCC/FCC teams.

We hope to continue to see improvements in both service utilization and birth outcome indicators, especially for those enrolled in MCC. We learned that the majority of the Medicaid women who are getting into PNC late or not at all, are those who are also not in care coordination: 57%. This is an issue in all three of the BLP program regions. In each of the areas, there is a substantial number of women whose births were paid for by Medicaid and who either never received prenatal care or received it very late in pregnancy… and who were *not* enrolled in care coordination: 482 (East), 551 (Triad), and 269 (Northeast). A disproportionate number of these Medicaid women who are slipping through the cracks are African American: 81% (East), 61% (Triad), and 71% (Northeast).

Interagency / Program Coordination: The Northeastern *Baby Love Plus* program operates in five of North Carolina's rural counties that each have limited health and social services resources, well developed but under-funded public health programs, and a range of private sector medical and social service institutions. Within the confines of such resources, the Northeastern region struggles with continued disparities in infant mortality and other key health and welfare issues. One recommendation that is already being addressed is more explicit partnership between the Healthy Start program and local groups such as the local Cooperative Extensions, congregations participating in the Ministry of Health programs, and successfully engaging clinical providers in the region as Consortium members. Activities suggested include sharing strategic planning and scheduling regular communications between workgroups, sub-committees, and representatives of each local partner agency. Additionally, working through local churches and the local agencies that serve targeted neighborhoods is likely to move the program more effectively into concrete and effective partnerships. The community grants program of *BLP* is another strategy that underwrites this effort, and should be continued, but with more rigorous evaluation and accountability for reaching stated objectives. While there has been considerable network and relationship-development during the project period, this is an area that the program continues to strengthen and develop.

Local Ownership: One reality that hampers true local ownership and engagement of the local Consortium is the basic structure of the Program, being State-driven. The *BLP* program is administered by the State's Title V offices through contracts with local health departments, with authority and decision-making occurring within a state bureaucracy. As such, it is structurally not set-up to foster true local ownership; the locus of control is necessarily with the State and its paid staff, in terms of how dollars are allocated and the basic design of the program. The State's hands are tied as well by Federal guidelines that promote Healthy Start models and delineate which services will receive funding (and which will not). Local input is focused therefore more on the details of implementation, rather than on design or decisions about priorities for the local situation. There has been a range in level of support and interest from local agency leadership, and this may in part be due to varying degrees of comfort with a lack of control or autonomy regarding grant resources and their expenditure. Future plans are in place to assist BLP Consortia in program regions to consider incorporating as 501(c)3 entities, thus enabling them to receive and dispense funds independently. This decision is ultimately in the hands of local community leadership and will be determined by Consortium Board and key partners.

The Importance of the Infant Mortality Issue: Educating consumers and consortium members about infant mortality and the Northeastern region's related statistics has emerged as a key issue and recommended activity, given survey respondents' lack of knowledge about the importance of, and their level of confusion on this issue. Until staff and consortium members recognize the importance of infant mortality and the racial disparity of infant mortality (African Americans have two to three times the infant mortality rate of Whites) in their region, it will be difficult to fully address and target program activities to address this profound problem.

A number of educational efforts have already taken place, but an ongoing and extensive public information campaign is recommended with concrete factual information about preterm birth and related risk factors and their prevalence. In addition to reaching consumers, such a campaign should include conducting in-services with *BLP* staff, especially outreach workers and providing information to collaborating agency personnel (WIC staff, FP clinic staff, Child Services

Coordinators, Maternity Care Coordinators, prenatal nurses) to update them on local data for their county and the residents that they serve.

Need for Greater Awareness of BLP and for Outreach: Community survey respondents indicated concerns about the fact that not everyone who could benefit from the BLP Program knew about the Program or appropriately was linked to services. BLP's community marketing efforts and outreach workers (Community Health Advocates or CHAs) continue to attempt to reach these people, but efforts need to continue and perhaps be intensified or better targeted. For example, very few respondents (only 10.1%) associated the BLP Program with outreach workers/CHAs. This needs further investigation to determine whether it is an issue of poor saturation among our target audience or whether our outreach workers are reaching the intended audience, but just not being identified with the BLP program, specifically.

Recommendations for the future include reducing expected contact numbers for the CHAs and improving intensity of contacts/having better coordination with referral agencies to know if families have been able to access the services they need. Respondents also suggested that outreach workers should continue going door to door, provide help with making appointments, and do more presentations for different groups (like local businesses or hair salons). One consumer encourages the outreach workers to be persistent in their efforts and to have patience:

> *They [CHAs] need to at least come to the homes and try to reach pregnant mothers and not give up after one or two trips to the home. Even if the mother doesn't comply, they [the outreach worker] should try and be very sensitive to people's situations."*

Unintended Pregnancy, Poor Understanding of Fertility
The survey tells us that there are very high rates of unintended pregnancy — 65.2% of women interviewed said that they either did not want to be pregnant at that time (46.4%) or that they never wanted to be pregnant (18.8%). There were also very high rates of unplanned pregnancy (eighty percent were unplanned, i.e., they stated that they were not trying to become pregnant). Despite not wanting to be pregnant, most respondents (60.9%) said they were not doing anything to prevent a pregnancy, the main reasons given being that (1) they did not think that they were fertile at the time (19.1%) or at all (9.5%) or (2) that their partner didn't want to use anything (14.3%). These rates are all higher than NC State averages for the respective indicators (compared with PRAMS African American respondents), which in themselves are quite high compared to national averages — and are reason for concern. Questions arise as to how to address these difficult issues. Access to services appears to be very good, and is not reported as a barrier to family planning. This is an area for further work to better understand the psychosocial, family dynamics, communication and partnership issues within relationships, and the inter-relationship between the stressors of planning related to daily life challenges and the stressors related to decisions and behaviors required to effectively manage health and fertility.

Levels of Stress, Need for Social Supports, Addressing Depression and Family Violence Stress was increasingly noted as a key risk factor that needed to be addressed by the program. While stress is a normal part of everyday life, managing stress and having major life-event stressors during pregnancy present special challenges. As mentioned above, depression is a common

response to being overwhelmed by stress, and can be incapacitating. Over half the women surveyed reported some level of depression (56.5%), with 8.6% saying they were "very depressed". Despite these symptoms, very few sought help. The evaluation surveys also showed high levels of experiences with physical abuse and partner violence, which is linked to stress and heightened during times of vulnerability, such as during pregnancy. When asked about experiences with physical abuse and partner violence, close to nine percent report that someone had pushed, hit, slapped, choked, or physically had hurt them in some way during their pregnancy. In one-third of these cases, it was the husband or partner who was the perpetrator. Additionally, women report that prior to pregnancy, 8.7% experienced some form of violence by either a husband or partner or anyone else. Comparable State figures are high as well with 11.4% for women experiencing any physical violence in the year prior to becoming pregnant, and 7.8% of NC African American women reporting violence while pregnant. These data show that women in the Northeastern project region continue to report extremely high levels of stress, often higher than other Medicaid women in NC. A major area of concern, therefore is how to identify effective ways to provide support to these families? How to empower them so they can better cope themselves with inevitable stressors of everyday life? This is not only an issue of increasing awareness, but providing services that matter and make a difference…what services will help? What are good times and opportunities to become involved? How can these issues be better addressed within our existing portfolio of services (PNC and MCC/Outreach/ WIC)?

Recommended Program Additions:

Two Year Post-Partum Follow Up

Another recommendation requiring additional resources but within the existing BLP Program's scope is the frequently expressed wish that case managers, or Maternity Care Coordinators (MCCs), could follow mothers up to two years post-partum. The reasons for this recommendation were to be able to extend the trust established during pregnancy, to build the relationship with the family, and to empower the client during her post-partum transition.

Following clients for two years would also help to ensure *either* appropriate baby-spacing, or, at the very least, positive pre-pregnancy / early pregnancy behaviors (folic acid, no alcohol, tobacco, etc.). Since recent research has identified the importance of spacing babies at least two years apart, as well as the importance of positive intervention in the pre-pregnancy and very early pregnancy periods, following clients for two years post-partum is more compelling than ever before. Results from the consumer survey of post-partum clients indicated high prevalence of pregnancy unintendedness, both for mistimed as well as unwanted pregnancies. Extending maternity care and women's health services well into the post-partum period may provide key supports during this stressful transition and reinforce the healthful benefits of planning a subsequent pregnancy.

Conclusion

The local evaluation of the Baby Love Plus program assessed each of the three program components, Case Management, Outreach, and Education and Training — as well as the Regional Consortium, with the primary focus being reduction of minority infant mortality and morbidity and improved perinatal health for those women most at-risk. Additionally, as mentioned above, the evaluation was actively involved in the Regional Consortium's efforts to plan and initiate the Local Health System Action Plan in 2005-06, during the subsequent project

period by providing technical assistance and data as needed. Finally, the evaluation team has assisted with required reporting protocols and other Healthy Start information activities, and worked closely with the management team in producing needed information for continued funding.

Dissemination Plans/Utilization of Results

The BLP-Northeastern staff along with the evaluation partners plan a series of releases as dissemination strategies for the findings of the BLP Program in the Northeastern region. In keeping with the participatory approach that has been the foundation of the overall program, the findings will be shared with the Regional Consortium and its appropriate sub-committees. Based on their feedback, strategies for dissemination will be incorporated into the annual Action Plans and activated throughout the project year. Products will be designed using appropriate reading levels and information styles. It is anticipated that we will hold a series of briefings for the Ministry of Health program staff, and have several Executive Summary pieces developed that can be distributed to interested public health leaders in the community. Local staff in collaborating agencies will be called upon to help interpret findings, and once completed, the results will be disseminated through these partners as well. We plan to develop fact sheets for selected topics related to key risk factors for the local target communities. These will be four pages (maximum) with general information about the risk factor and specific data and outcomes for each local community, based on data from the Baby Love files and primary data collected through BLP field staff. The fact sheets will be provided to BLP outreach workers in addition to local liaisons and Consortium leaders. Finally, results will be prepared and submitted for presentation at the regional and national levels at APHA and AMCHP and CDC's MCH meetings. The data for these results will not be available until 2006. However should important findings on process indicators become apparent before that time, then we will prepare summaries for presentation. We also plan to collaborate with researchers at the NC State Center for Health Statistics who had conducted original evaluations of the NC Baby Love program in 1992, and conduct an update of this evaluation using BLP project data. These results will be submitted for dissemination through the State's *Health Findings Briefs*, a series of monographs that are produced periodically and sent to health practitioners, public health leaders, and researchers throughout the State.

Reports/Publications/Products/Data Collection Tools/Study Instruments

A number of items have been produced as part of the NC Baby Love Plus Program's Local Evaluation. To date, the majority of items relate to data collection, community surveys, and presentations or preliminary summaries of findings. While we await final outcome data, we have prepared a number of interim reports and made presentations to local groups, Consortia, and staff. Any of these items are available upon request

Evaluation and Data Reports Produced

The evaluation team has produced a number of reports and data summaries. The most extensive of these was the *Background Summary* compiled as part of the LHSAP. This report analyzes Regional trends in infant mortality over two decades, compares rates of infant mortality, low birth weight, and prematurity for the Northeastern region to the State for the priority population being served. Additionally, the report summarizes the results of the 1999 Needs Assessment conducted as part of the pre-project Planning Grant that included town hall meetings and

interviews with community leaders, case managers, and clinical specialists from the five counties in the project area. A Reader's Guide to the Needs Assessment Report (Attachment H) was prepared to assist Consortium members and other interested partners in accessing the information. Three times yearly, a standard report is produced for the program's management team and presented at meetings for review with the evaluation partners. Program and administrative data have been provided by the evaluation team as scheduled (quarterly, semi-annually, and annually depending on the program area) and were presented February, June, and October to *Baby Love Plus* Program staff. Most program data were collected on summary sheets by BLP staff or regional managers and then provided to the evaluation team via email. Results of computer runs using vital record files were provided by the State to the Sheps Center as they became available and were requested for analysis. Frequencies and selected bi-variate summary data were included in program reports, as required. Specific analyses and detailed descriptions of how evaluation data were used over the past year is as follows, according to each data source (See Data Flow Chart submitted in original application). More detailed information about the periodicity, field logistics, and specific use of each type of data is included in the *Data Forms and Procedures* described above.

Data Collection Forms

1. Monthly Contact and Referral Logs
2. Regional Consortium Manager's Report Form
3. Training Assessment Form
4. Administrative Index (active during first two years of program)

Survey Instruments and Questionnaires

1. Consumer Survey Instrument
2. Consortium Survey Instrument
3. Systems Survey Key Informant Instrument
4. BLP Transportation Satisfaction Survey

Slide Shows / Presentations / Reports

1. Trimesterly BLP Team Meeting Program Reviews (sample from July 2004)
2. Evaluating and Monitoring Community Partnerships, Building Bridges Conference
3. Overview of NC *Baby Love Plus* Program Intervention Models, and Evaluation Plans
4. Description of NC Healthy Start Models, Populations Assessed, Data Sources, and Program Objectives
5. Perinatal Period of Risk Analysis and Slide Presentation

Training Materials

1. Consumer Survey Overview
2. MCH Data to Action Workshops
3. Interviewer Training Manual for BLP Consumer Surveys
4. Evaluation Overview for BLP Staff

VII. Fetal and Infant Mortality Review (FIMR)

Northeastern NC Baby Love Plus funds were not utilized for FIMR. FIMR is being developed utilizing MCHB Title V funding.

VIII. Products

The following curriculums or training materials were developed using Healthy Start 2000 – 2003 grant funding.

- *Counseling Women Who Smoke Guide* (Attachment J)
- *Healthy Mother Healthy Baby* brochure for first time expectant parents (Attachment K)

Healthy Start funds were also used to produce the Annual Healthy Start Training Institute (Attachment L).

IX. Project Data

All required project data has been previously submitted under separate cover.