Illinois Department of Human Services
Healthy Start Impact Report

Section I: Overview of Racial and Ethnic Disparity Focused On By Project

Identify the racial, ethnic or other disparities that your project focused on. Highlight from your initial community needs assessment the data that led to your community's decision to focus on the identified disparities.

The Goal of the DHS Healthy Start Project is to improve access to quality maternal and child health services in order to reduce the high rate of infant mortality and minimize the racial disparity that exists in the Project Area (includes six community areas in Chicago).

Data/information extracted from vital records (birth and death certificates) filed with the Illinois Department of Public Health, was used to define and compare the racial disparity that exists in MCH health status indicators, as well as their determinants and contributing factors for residents in the Project Area. The poor health status of mothers and infants and the wide racial disparity in MCH indicators for the DHS Healthy Start Project Area was empirically defined by the Community Needs Assessment.

1. Racial/Ethnic Composition of Healthy Start Project Area

The data in Table 1 below finds that the racial composition of the birth cohort in the DHS Healthy Start Project Area differs significantly from the birth cohorts for the State of Illinois and the City of Chicago. Using data/information extracted from birth certificates filed with the Illinois Department of Public Health between 1991 and 2002, the Illinois birth cohort for the most recent three-year period (2000-2002) had a racial composition that was 77.2% white and 18.1% black, and 22.1% of all births were Hispanic. The City of Chicago's birth cohort for 2000-2002 was 58.2% white, and 37.4% black with 37.3% Hispanic. Among the Project Area live births, 45.3% were white and 50.8% were black with 23.8% Hispanic.

TABLE 1
PERCENT LIVE BIRTHS BY RACE/ETHNICITY
FOR RESIDENTS OF ILLINOIS, CHICAGO AND PROJECT AREA: 2000-2002

Race/Ethnicity	Project	Chicago	Illinois
White	45.3%	58.2%	77.2%
Non-White	54.7%	41.8%	22.8%
Black	50.8%	37.4%	18.1%
Hispanic	23.8%	37.3%	22.1%

2. Targeting "Hard to Reach High Risk" Women in Project Area

Using the data captured from the individual patients' Risk Assessments, HBA described the "hard to reach, high risk" pregnant population served by the DHS Healthy Start Project. Using the frequency distribution of risk factors identified (see Appendix 1), HBA created the following *risk profile* of the "typical" Healthy Start *Pregnant Participant*. This description can be used to "put a face" on the "hard to reach high risk" pregnant women served by the DHS Healthy Start Project. Below is the *risk profile* for 2003 and 2004 pregnant participants:

The "typical" DHS Healthy Start Pregnant Participant can be described as an inner city, black, female from 15-34 years of age that is at high risk for a poor outcome of pregnancy. The "typical" Pregnant Participant is likely to be of low educational attainment, have been homeless, and in poor health, with a history of many pregnancies, and a preterm birth.

3. Community Needs Assessment

Table 2
Chicago Project Area
Black/White Ratios on Key MCH Indicators: 2000-2002

Indicator	Chicago Project Area		Ratio
	Black	White	Black:White
Health Status 1			
Infant Mortality	17.2	6.3	2.7:1
Neonatal Mortality	10.5	3.5	3.0:1
Postneonatal Mortality	6.7	2.9	2.3:1
Determinants 2			
VLBW (<1,500 grams)	3.4	1.2	2.8:1
LBW (<2,500 grams)	N/A	N/A	N/A
Contributing Factors 2			
Low Prenatal Care	8.8	3.3	2.7:1
Births to Teens	24.4	9.4	2.6:1
Single Moms	N/A	N/A	N/A

1. Rates per 1,000 live births. 2. Rates per 100 live births.

The comparisons made between rates already achieved by a subpopulation (read white births) in the Project Area to other subpopulations (read black births) that have not achieved these rates, does in fact, identify an "opportunity" to evaluate and reestablish priorities in preventing excess infant mortality and morbidity.

The initial Community Needs Assessment provided data that led the DHS Healthy Start Community to focus on identified racial disparities not only in *Health Status Indicators* (i.e.,

infant mortality), but also the *Determinants* (i.e., birth weight), and *Contributing Factors* (i.e., low prenatal care) that are known to impact health status. Table 2 above highlights the racial disparity that existed in the Healthy Start Project Area in 2000-2002.

A review of the black/white ratios for key MCH indicators finds wide disparity between black and white births in the Healthy Start Project Area for 2000-2002. This data suggests that wide racial disparity existed for Health Status Indicators, Determinants and Contributing Factors.

a. *Health Status Indicators*: During 2000-2002, the largest racial disparity was found to be in the neonatal mortality rates. The neonatal mortality rate for black births in the Project Area was 10.5 while the white neonatal mortality rate was 3.5. This represents a black/white ratio of 3.0 black neonatal deaths to 1 white neonatal death. This disparity suggested that the access, availability, and/or acceptance of risk appropriate care to black newborns in the Project Area may differ from that of whites.

b. *Determinants:* This evaluation finds that the black/white VLBW ratio for births in the Project Area were 2.8:1 for 2000- 2002. This finding suggests that the access, availability or acceptance of maternal health services to black females in the Project Area may differ from that of white females.

c. *Contributing Factors:* This evaluation finds that two direct contributing factors had wide disparity in the black/white ratios during 2000 - 2002. Low prenatal care (2.7:1), and the percent of teen births (2.6:1) had wide discrepancies in the black/white ratios. This finding suggests that the availability of education and information services that effect knowledge, attitude, and behavior may differ between white females and black females in the target area. This finding suggested that both outreach and education/information services should be examined to determine if the subpopulations know they exist, are accessible, and are acceptable to these subpopulations in the target area.

4. Recommendation: "Further Analysis of Underlying Causes is Required"

In order to better target DHS efforts to improve racial disparity, additional analysis to better understand and define its underlying causes is required and planned. CDC has identified a useful tool for defining and examining the underlying causes of preventable mortality and racial disparity called the "Perinatal Periods of Risk Analysis" (PPOR). The PPOR Analysis has been recommended for implementation in Healthy Start Projects not only by CDC, but also by HRSA.

HBA has incorporated the PPOR Analysis into the Evaluation Plan for the Healthy Start Project and continues to participate in "Level II Training" sponsored by the Bureau of Maternal and Child Health related to implementation of the PPOR Analysis.

Section II: Project Implementation

Using as a framework the five Healthy Start Core Services (Outreach and Client Recruitment, Case Management, Health Education and Training, Interconceptional Care, and Depression Screening and Referral) and the four Core Systems-Building Efforts (Local Health System Action Plan, Consortium, Collaboration and Coordination with State Title V and Other Agencies, and Sustainability), identify how your Healthy Start implemented each service and system intervention. For each one, answer sequentially the following:

A. Describe how you decided on your approach to each service and each Core Systems-building efforts and the rationale for your particular approach based upon your particular community's needs, service system and its challenges and assets. For example, you might acknowledge that in your area, improving the quality of available of services was more crucial than increasing their number and so you focused on quality improvement in your Local Health System Action Plan.

B. Identify the components of your intervention and the resources (including personnel) needed to implement intervention. Note any changes over the project period and the rationale for the changes. For example, you might have decided that using indigenous community workers for the Outreach required a great deal of support and training and therefore you gradually changed to an intervention where the Outreach workers and case managers had more frequent contact.

C. Identify any resources or events (for example, your state experienced a budget shortfall) that either facilitated or detracted from successful initiation and implementation of each intervention.

The description of the five Healthy Start Core Services and four Core Systems-Building Efforts is provided below:

Outreach and Client Recruitment

A. Outreach was conducted by each Healthy Start Family Center through the CFCM and WIC programs. The Outreach workers at each Family Center are knowledgeable of their community and are able to engage and recruit women into services. The target population is families with a pregnant woman, an infant, or a child under two. Ongoing support and incentives (small pregnancy and parenting-related gifts) are used to encourage women to engage and remain in services until their children reach two years of age.

B. This approach is consistent with the Department's strategy of having Chicago Family Care Management (CFCM) serve as the basic program and Chicago Healthy Start provide intensive case management to the clients at highest risk based on the risk criteria described in the section on case management.

The Chicago Healthy Start Initiative used three broad approaches to outreach. First, the five Family Centers are indirectly linked electronically to the Department's local offices through a monthly data exchange. Second, pregnant women and families with young children from the Project Area who enter the WIC program will be referred to the Chicago Healthy Start Initiative. Third, each of the Family Centers conducted more traditional Outreach activities to find potentially eligible women and inform them of the services available through the initiative.

Each month, the Department distributed to local Family Case Management agencies information about newly Medicaid-eligible infants and pregnant women. This information is collected from the Department's local office staff across the state at the time that a customer is determined to be eligible for assistance through the Temporary Assistance for Needy Families (TANF), Medicaid or State Child Health Insurance programs. Identifying information and, for pregnant women, the expected date of confinement, are entered in the Department's Client Information System, which is a sub-system of the state's Medicaid Management Information System. This information is extracted from the Client Information System during the first weekend of each month and passed electronically to the central database for the Department's Cornerstone Management System. From there, the following weekend, the information is downloaded overnight to local Family Case Management agencies' Cornerstone databases on the basis of the eligible family's place of residence (by county downstate and by ZIP code area in Cook County). Local Family Case Management case managers and Outreach workers then use this information to contact Medicaid-eligible families and inform them of the assistance available through the Family Case Management program, including medical care, WIC and other services.

The WIC served as an important source of referrals for the Chicago Healthy Start Initiative. There are 13 WIC clinics and five WIC Food Centers in the Project Area. In a recent survey of Medicaid-eligible women in Chicago who were not participating in either the WIC or Family Case Management programs, 91 percent of the respondents had heard of the WIC program. Pregnant women who are not eligible for Medicaid (or who have not yet made application) may seek out WIC services as their first contact with the public health system. The Department has been emphasizing the integrated delivery of WIC and Family Case Management services for two years because of its dramatic impact on very low birth weight and infant mortality. The goal of this effort has been to ensure that families—especially pregnant women—who are active in one program are also active in the other one. Referral relationships between the WIC clinics and Healthy Start Family Centers in the Project Area are well established.

C. As will be described throughout this report, the State of Illinois encountered a budget shortfall; however, the funding of Maternal Child Health Services was expanded.

Case Management

A. The Case Management is the nucleus of the service delivery system provided at the Family Centers.

   The Chicago Healthy Start Initiative was built on the foundation of the Family Case Management program. This program conducts outreach activities and provides case management services to low-income (below 185) percent of the federal poverty standard) families with a pregnant woman or an infant. The program operates statewide. Case management activities are conducted in accordance with the requirements for outreach and case management contained in the Department's administrative rules (77 Illinois Administrative Code 630.220), a copy of which is presented in Appendix 4.3. The Family Case Management program is supported by State general revenue funds, and the State uses these funds to obtain matching funds as an administrative claim from the federal government through the Medicaid program. The case managers in the Family Case Management program have a wider variety of academic and experimental preparation for their work roles and carry caseloads that range from 150 to 200 cases at any given point in time. The Chicago Healthy Start Initiative was designed to enhance the Family Case Management program by using more highly trained case managers to work more intensively with a smaller number of higher-risk families. The Chicago Healthy Start Initiative also provided services through two years of age, which is one year longer than the Family Case Management program.

   The combination of WIC and Family Case Management services has been demonstrated in three consecutive evaluations to be effective in reducing very low birth weight, low birth weight and infant mortality when program participants are compared to Medicaid-eligible women who did not participate in either program during pregnancy. Table 65 presents the very low birth weight, low birth weight and infant mortality rates among Medicaid-eligible women in Illinois who did and did not participate in the WIC and Family Case Management programs during pregnancy. The groups were identified by matching Medicaid eligibility, Cornerstone and Vital Records databases. Participation in WIC and Family Case Management achieves a reduction in very low birth weight greater than one half, a reduction in low birth weight of one third, and a reduction in infant mortality greater than one half.

B. The intervention and resources including personnel were already established during the demonstrations and mentoring phases. The role of the case manager is to empower families to assume responsibility for their health and welfare. One goal of the case management process is to help participants or their care givers learn to accept responsibility for their own lifestyle and promote their own health. Another major goal of case management is to enhance the participants' or their care-givers' strengths and resources by teaching them skills for seeking out and using individuals and agencies in the community who are available to meet a wide variety of human needs. At first, the case manager will likely be responsible for most of these activities. As times passes, the participants or their caregivers will ideally participate more actively, while the case manager adopts a more supportive role. Successful case management relies on the

education of participants, facilitation of access to services, coordination with service agencies, follow-up on services delivered, assistance with scheduling, and case management assessments to determine medical, psychosocial and environmental risks. The case management process includes the following activities:

- Assessment of needed health and social services
- Development of an individualized care plan
- Referral of participants to appropriate providers within the community
- Ongoing follow-up with participants or service providers from initial identification though case closure to determine whether participants have accessed services
- Periodic reassessment of participants' needs
- Advocacy to assist participants in accessing
- Procedures for terminating the professional relationship between the participant and the case manager when the participant no longer requires case management

The case management process used in the Chicago Healthy Start Initiative begins with a comprehensive assessment. By administrative rule, the assessment addresses the need for health, mental health, social, educational, vocational, substance abuse treatment, childcare, transportation or other services. The additional assessments include:

- A nutritional assessment
- A psychosocial assessment, including composition of family, evidence of parent-bonding, parenting skills and education of parents
- Support systems available to parents or care-givers
- Social and health services currently used by the family, including sources of primary care and emergency care
- Environmental assessment, including at least the condition of housing, availability of utilities (water, heat, light, cooking, refrigeration, sanitation, etc.) and risks of unintentional injury
- Developmental assessment of infants and children

Following assessment, a service plan is developed that reflects the strengths and service needs of each participating family. The development of the service plan may include discussions with the participant and with other providers that will be identified in the plan. The individual care plan includes:

- Verification of eligibility for all payment mechanisms for medical care
- Referral, if necessary, for physician services
- A list of all of the service providers involved with the participant
- A list of the agencies to which the participant will be referred
- A program list and plans for problem resolution

Families were selected for the Chicago Healthy Start Initiative based on the risk factors presented below. The intervention model assumes that families will require more intensive (frequent) case management support than can be provided through the Chicago Family Case Management program. Therefore, as previously stated, Healthy Start case

managers had face-to-face contact with pregnant women at least twice per month, and at least one of these contacts will occur in the family's home.

- Alcohol or other substance abuse (excluding tobacco) that continues during pregnancy
- Diseases that affect the outcome of pregnancy (such as diabetes or hypertension)
- A prior pre-term birth
- Grand multi-parity (parity greater than four) or repeated short inter-pregnancy interval (third child expected within 40 months)
- Human Immunodeficiency Virus (HIV) infection or repeated sexually transmitted infections (excluding bacterial vaginosis)
- Age less than 15
- Current multiple pregnancy
- Domestic violence during the current pregnancy

Further, women who fact two or more of the following circumstances qualify for case management services:

- Low educational attainment (over age 18 with less than a 10^{th} grade education)
- Homeless or in temporary housing
- Previously incarcerated or placed under house arrest
- One or more children currently or previously in the care and custody of the Illinois Department of Children and Family Services

During the project period the Department reduced the number of Family Centers from five (5) to four (4). This change was due to the Chicago Urban League making the decision to close the medical component of its Family Center in 2001. Two of the remaining four Family Centers, Near North and Henry Booth House, agreed to provide services to the communities that were formerly served by the Chicago Urban League Healthy Start Family Center.

C. As previously mentioned the State provided an increase to improve MCH services. There was no adverse impact on the Chicago Healthy Start program.

Health Education

A. During the early stages of the project the Department hired a health educator with expertise in maternal and child health to conduct health education to the Outreach and Case Management staff at each of the family centers. Additionally, the health educator was responsible for conducting health education sessions for the clients at the respective Family Centers. Staff education was designed to develop the abilities of the case manager, case manager assistants and Outreach workers to intervene effectively with the families they served. It was anticipated that staff training programs would be conducted every other month during the year with staff from all of the family centers in attendance.

B. During the project period it was necessary to change the Health Education Component to enhance cultural competence. With input from both the Chicago Healthy Start Consortium and the Family Centers, it was decided to have the Family Centers provide the Client Health Education and to rotate staff education to ensure the most up to date information available. Extensive sessions on MCH topics were provided to Case Management and Outreach staff by such agencies as Planned Parenthood, SIDS of Illinois, and Chicago Health Connections.

These are summarized below:

Pre-Term Labor

Audience: Case Managers
Rationale: The program targets women who are at risk of premature delivery, which places their infants at increased risk of severe morbidity or death.
Goals: To provide the client with a simple, clear and easy understanding of the normal growth and development of a baby while in the womb.
Activities: The health educator uses a PowerPoint presentation and handouts to discuss the signs and symptoms of prematurity. The class includes a discussion of the ways that stress affects pregnancy, strategies for stress reduction and what to do if she experiences signs of pre-term labor. The session includes time for discussion.
Time Frame: Two and one half hours.
Evaluation: Pre- and post-testing.

Normal Infant Growth and Development

Audience: Case Managers
Rationale: Clients need to have comprehensive, easy-to-understand information to ensure that infants reach their full potential.
Goals: To provide clients with a comprehensive understanding of the Stages of Infant growth and Development
Activities: The health educator uses a PowerPoint presentation and handouts on infant growth and development for ages and stages of development from two to 24 months. The curriculum covers well child visits, breastfeeding and the development of language and motor skills. The format includes time for discussion.
Time Frame: Two and one half hours.
Evaluation: Includes pre- and post-testing.

Women's Health After Pregnancy

Audience: Case Managers
Rationale: Populations served by Healthy Start have differing notions on activities after pregnancy.
Goals: To provide women with culturally appropriate information concerning their health after pregnancy.

Activities: The health educator uses a PowerPoint presentation and handouts on women's general health and family planning methods. Contraceptive methods include condoms, diaphragms, IUDs and oral contraceptive methods. The format includes time for discussion.
Time Frame: Two and one half hours.
Evaluation: Pre- and post-testing.

Sexually Transmitted Diseases HIV/AIDS

Audience: Case Managers
Rationale: Sexually active women that do not practice safe sex are at risk for being infected with any sexually transmitted disease. It is necessary to provide program participants with accurate information on the various diseases and how to reduce the risks of infection. Over 60 percent of new AIDS cases are among African American women.
Goals: To provide program participants with up-to-date information on STD's/HIV.
Activities: The health educator uses a PowerPoint presentation and handouts on STD/HIV, including chlamydia, genital warts, gonorrhea, herpes, hepatitis, HIV/AIDS, and syphilis.
Time Frame: Two and one half hours.
Evaluation: Includes pre- and post-testing.

Substance Abuse Prevention

Audience: Case Managers
Rationale: Drug and alcohol use is associated with other forms of unhealthy behavior that puts the mother and unborn child at risk for adverse perinatal outcomes.
Goals: To educate mothers of risks and problems associated with drug use, including alcohol; to reduce the number of substance-exposed infants; and to identify treatment and prevention resources linked with Chicago Healthy Start Family Centers.
Activities: The health educator uses a PowerPoint presentation and handouts on dangers associated with alcohol, crack cocaine, marijuana, heroin, etc., including risk of miscarriage, mental retardation and growth retention. Session will include questions and answers, discussion and treatment facilities associated with the respective Healthy Start Family Centers.
Time Frame: Two and one half hours.
Evaluation: Pre- and post-testing.

Identification of Perinatal Depression

Audience: Case Managers
Rationale: Nearly 75 percent of all postpartum women experience the "baby blues."
Goals: To provide women and their significant other with an overview of perinatal mood disorders with the goal of identifying signs and symptoms.
Activities: Women will receive an overview of the condition, an explanation of each of the physical symptoms, and the mental status and behavioral reactions associated with it. Session includes question and answer discussion.

Time Frame: Two and one half hours.
Evaluation: Pre- and post-testing.

Smoking Cessation

Audience: Case Managers
Rationale: Cigarette smoking impacts both the mother and the unborn child. It can raise the risk of miscarriage, reduce the ability of the lungs to absorb oxygen, and increase the likelihood of SIDS.
Goals: To provide the client with an understanding of the risks associated with smoking and with methods to help them reduce or eliminate this behavior.
Activities: A presentation on the contents of cigarettes will be given in addition to complications associated with smoking. Participants will be given tips on quitting and easing withdrawal, along with substitutes when clients get the craving. Participants will also be linked to the Illinois Department of Public Health's smoking cessation "Quit Line."
Time Frame: Two and one-half hours.
Evaluation: Pre- and post-testing.

Parenting Sills—Discipline

Audience: Case Managers
Rationale: Participants in the project have differing views on what's appropriate discipline. To achieve the goals of the project requires that the clients obtain basic information in this area.
Goal: To provide the participant with the ability to recognize the difference between discipline and abuse and to enable the participant to understand the impact family systems have on child discipline.
Activities: Session will start with a mock talk show panel discussing child discipline and punishment. It will include role-playing and with participants formulating a definition of discipline versus punishment. Session ends with clients reviewing the difference between child discipline and child abuse.
Time Frame: Two hours.
Evaluation: Pre- and post-testing.

Domestic Violence—Healthy Relationships

Audience: Case Managers
Rationale: Domestic violence is a pattern of psychological abuse, threats, intimidation, isolation, or economic coercion used by one person to exert power over another in a context of dating, family, or household relationship. Pregnant or parenting females in Healthy Start have either been the victim or knows a close friend or relative who has been impacted by domestic violence.
Goal: To provide the participant with the myths and facts about this public health problem with the goal of providing the client with the skills to recognize it and to take positive steps to end it if they are impacted by it.

Activities: Will include both group discussions about the topic and a presentation that covers myths and facts. Description of the cycle of violence: the tension-building phase, acute explosion, reconciliation. Participants will be informed of resources associated with the Chicago Healthy Start Family Center.
Time Frame: Two and one half hours.
Evaluation: Pre- and post-testing.

Breastfeeding

Audience: Case Managers
Rationale: Breastfeeding promotes moth and infant bonding, improves the infant immune system and also can improve maternal health.
Goals: To provide the participants with an understanding of the benefits of breastfeeding and ways to perform it successfully.
Activities: A presentation on the benefits of breastfeeding, composition of breast milk, and bonding associated with breastfeeding. Session will also include question and answer discussion.
Time Frame: Two and one half hours.
Evaluation: Includes pre- and post-testing.

Sudden Infant Death Syndrome

Audience: Case Managers
Rationale: Sudden Infant Death Syndrome is a major cause of death in infants from one month to one year of age. It is a recognized medical disorder with long-lasting effects on the entire family. Yes the risk of SIDS can be reduced significantly by placing the baby on his or her back, ensuring the baby is in a smoke-free environment and by keeping the baby from being overheated.
Goal: To provide clients with an understanding of SIDS and ways to minimize the associated risks.
Activities: Presentation on SIDS as outlined above.
Time Frame: Two hours
Evaluation: Includes pre- and post-testing

Interconceptional Conceptional Care

A. The Department worked with the Consortium to develop and implement an interconception care component that would assist new mothers achieve goals that would help them achieve their full potential. There was a consensus that the services provided had to be more than just Family Planning, but more of a goal-oriented approach to healthy lifestyles to achieve good perinatal outcomes by having a mother be proactive in deferring a future pregnancy until she was ready to nurture the infant. As a result, the program was titled Interconceptional Case Management.

B. The components of the Interconceptional Case Management Component are a re-screening, development of a care plan, group educational sessions, and incentives. Specifically, once a mother delivers she is reassessed to determine her risk status. This also includes re-screening for perinatal depression. If the mother is determined to be at risk, she and the case manager will develop a care plan that includes more than the selection of a Family Planning Method, but life-oriented goals such as obtaining housing, career development or educational achievement. Each of the Family Centers developed the group sessions that the client attends. These sessions covered subject matter such as self-esteem, stress reduction, well baby care, career counseling and parenting. As the client achieves goals that have been established in the Case Management plan, she is given small incentives. These incentives were found to be a very important component method of retaining the client in the Interconceptional Case Management Component.

C. The Department did not experience any adverse impact on this component due to budget issues.

Depression Screening and Referral

A. Accomplishments:

The Department has successfully implemented perinatal depression screening and intervention in all four Family Centers. Each Family Center has hired a mental health professional (a licensed clinical social worker or a licensed clinical professional counselor) to screen Healthy Start participants for perinatal depression and to either provide counseling or refer the participant to an appropriate mental health care provider.

A mental health professional from one of the Family Centers, members of the Consortium, and Department staff formed the Perinatal Screening Sub-Committee of the Consortium's System Integration Committee. This group was established to formulate recommendations for the implementation of perinatal depression screening. After an extensive series of meetings, the committee recommended administration of the Edinburgh Postnatal Depression Scale during pregnancy and during postpartum period.

A two-day training for staff was conducted on November 8 and 9, 2001, to introduce the tool and the protocol to the case management staff. In addition, at the request of the five other federally funded projects, training on the use of the Edinburgh scale was conducted in late January 2002. This training was organized by the Perinatal Depression Sub-Committee and was well received by the other federally funded Healthy Start projects.

The Department's MCH nursing component was a key participant in assisting the Healthy Start project implement the Edinburgh Scale and the service component. A chart that outlined symptoms of perinatal mood disorders was developed and is included in the impact report. See Attachment 1.

B. The Department's approach to the screening and referral of clients is identified in Part A. The critical component was to provide this service in a culturally competent manner.

To achieve this end the department has incorporated the elements that demonstrate cultural competency as outlined in Healthy Start Performance Measure 10. Specifically, the department has implemented the core functions of designing services to meet the needs of culturally diverse groups, identifies barriers and provides appropriate strategies to address them, and evaluates and monitors quality services via customer satisfaction surveys. Additionally, the department, through the Healthy Start Family Centers, employs culturally diverse and culturally appropriate staff and supports the provision of training and ongoing professional development for the Family Center in the area of cultural competence. In regards to providing services to address perinatal depression in a culturally appropriate manner, the Family Centers serve three racial/ethnic groups. These are African Americans, Latinos and Chinese. Chicago Healthy Start utilizes the Edinburgh Screening Tool.

The first step was to assure success in the screening process and to assure that the screening tool was properly translated to both Chinese and Spanish. It has been translated into many languages, so versions in participants' preferred languages were readily available.

The next step was to recognize that each population has its own set of cultural and religious values. For example, family beliefs among African Americans center around the challenges of single parenting. Other issues include racial discrimination and its manifestations in employment, education and housing. In the Latino community, the family is the first priority: children are celebrated, the wife fulfills the domestic role and the husband is considered the protector of the family. There is also a strong Roman Catholic religious tradition, mixed with ancient practices and herbal remedies. In addition there is a strong sense of divine providence (one's destiny is considered to be "in God's hands"). Chinese culture is similar to the Latino population in some respects—there is a strong belief in family and a subordinate role for women.

To effectively address Perinatal Depression, Chicago Healthy Start recognizes that the Edinburgh Postnatal Depression Scale (EPDS) is a screening tool and is not meant to diagnose Perinatal Depression. It is used to identify women who need to be referred for additional assessment, diagnosis and treatment if needed as part of a culturally appropriate case management system. This system takes into account the unique characteristics of the culture served and develops treatment modalities accordingly.

Specifically there is a negative connotation in the African American community concerning mental illness. Hence the case manager will approach the administration of the Edinburgh in the context of a stress identifier. In regards to the Spanish speaking population the Edinburgh is administered with the involvement of the client's male partner.

In the event treatment is required, the case manager will move forward in the manner most appropriate for the particular culture of the woman being served.

C. As previously mentioned, while the state of Illinois experienced a shortfall, it intensified its commitment to maternal and child health services.

The Department was asked to take the lead in 2002 in heading a statewide task force to develop recommendations to improve services in the area of Perinatal Depression. At the time Chicago Healthy Start was the only project providing services in this area. A cadre of professionals was assembled to participate on the task force, including staff from the State Mental Health Department and from advocacy agencies that included Postpartum International.

The task force developed a concept paper that included both short term and long term recommendations that are listed below.

Short Term:

- Distribute educational materials through DHS providers and other venues
- Train DHS providers and others to identify women and refer them for services
- Develop medication and treatment guidelines for primary care physicians

Long Term:

- Determine the most effective means to provide psychiatric consultation on the psychopharmacological treatment of women with postpartum depression to primary care physicians
- Develop a comprehensive system of services that includes case management, peer support, supportive services, and additional capacity for psychotherapy.
- Work with IDPA to obtain a Medicaid waiver that would extend eligibility to women receiving postpartum follow up to include the time required for treatment.

The task force has been successful in increasing the amount of public awareness. The work of the task force was submitted to the governor's office. A newspaper article that mentioned the work of the task force was submitted to the Division of Perinatal Systems and Women's Health. At the time Illinois was one of only four states to have such a task force. In May 2003 the governor of Illinois proclaimed the month Postpartum Depression Awareness Month.

The Department of Health Care and Family Services (formally called the Illinois Department of Public Aid) has established a payment mechanism for those agencies to screen pregnant women for Perinatal Depression using the Edinburgh Screening Tool. Finally, the task force helped establish the Illinois Postpartum Depression Alliance. The Alliance in turn established a hotline that provides information about support groups and specialists.

Local Health System Action Plan

A. As the Department is the Title V grantee and a sophisticated perinatal system was established, the Department was able to enlist the Consortium to establish priorities for the Local Health System Action Plan. The three priorities established were:
    - Implementation of Fetal Infant Mortality Review (FIMR)
    - Implementation of screening and referral for perinatal depression
    - Addressing the need for housing for TANF-eligible teens

B. During the project period the Department has been successful in addressing all three of the priorities established in the LHSAP. The Department encountered some problems in the establishment of its FIMR project. Initially, the Department planned to implement FIMR through the University of Chicago's perinatal center and its 33 affiliated hospitals. This required approval from each hospital's Institutional Review Board, which proved to be very time consuming. The Department developed an alternative approach and asked the Chicago Department of Public Health to identify cases and designate the FIMR project staff at the University of Chicago as its agents for conducting home interviews. They agreed to this approach. The FIMR project is now citywide and, since it operates under the auspices of the local health department, does not require separate review and approval by individual hospitals. No significant barriers were encountered in developing the perinatal depression screening component of CHSI. Housing, the third priority in the LHSAP, proved to be a very challenging issue. The Consortium was able to participate in a housing workshop with Congressman Danny K. Davis of the seventh congressional district. Additionally, the Consortium hosted the Deputy Commissioner for Housing in the City of Chicago, who provided resources for the Consortium in relation to housing.

C. No significant barriers were encountered due to budget constraints experienced by the state of Illinois.

Consortium

A. The Department recognized the Consortium as a key component of the Healthy Start Program. It served as an advisory arm for the project that provided the major stakeholders with a voice in the Service Delivery System.

B. The Department established the Consortium during the demonstration phase of the project. During the project period the Consortium had three functioning committees: the Executive Committee, which is comprised of the three officers and Department Healthy Start staff; the Data and Evaluation Committee, which is comprised of representatives from each of the four Family Centers; and the Consumer Mobilization Committees at each Family Center.

    During the project period the reorganizing of the Consumer Mobilization Committee was implemented. This committee was decentralized to permit each of the Family Centers to

better address the needs of the consumers at the local level. The Consortium meetings were restructured in order to let the consumers speak first at each Consortium meeting. This improved the productivity of the Consortium. It was through this process that changes were made in the Health Education Component and an important contact with the Deputy Commissioner of Housing for the City of Chicago was established.

C. The Department has not experienced any adverse issues with the Consortium due to budget issues.

Additional Elements

A. Highlight how the Consortium was established and identify any barriers that emerged in its establishment and how they were addressed.

Response

As previously mentioned, the Department established the Consortium during the initial phase of the project.

B. Briefly describe the working structure of the consortium that was in place for the majority of the implementation, its composition by rate, gender, and types of representation (consumer, provider, government, or other). Also, please describe the size of the Consortium, listing the percent of active participants.

Response

The Consortium's chairperson and secretary are Family Center managers. The Vice Chairperson is a consumer. As previously mentioned, the Consortium has three functioning Committees: the Executive Committee, which is comprised of the three officers and Department Healthy Start staff; the Data and Evaluation Committee, which is comprised of representatives from each of the four Family Centers; and the Consumer Mobilization Committee. During the course of the project the composition of the Consortium was mainly African American (87%). The Latino population decreased slightly to 10%, while the Asian American grew to 4%.

Females have historically been the majority gender of the Consortium, comprising 93% of the membership while males comprised 7%. The membership of the Consortium has been 50% consumers. During the majority of the project, the Consortium consisted of 65% consumers, 29% community-based agencies, and 2% private agencies.

During the course of the project, 60 percent of the Consortium membership was active. To be considered active, a member must attend 50 percent of the meetings. By the end of the project period the Consortium membership has grown to 75 individuals.

C. Describe the activities this collaborative has utilized to assess ongoing needs, identify resources, establish priorities for allocation of resources, and monitor implementation. Describe your relationship with other consortia/collaboratives serving the same population.

Response

Historically, the establishment of priorities and assessment of ongoing needs has been accomplished by the Consumer Mobilization Committee. This group helped redesign the health education component. It recommended the project invite the Deputy Commissioner of Housing for the city of Chicago to identify resources that consumers would use. In addition, the consumers recommended the Department hold a leadership conference. This was held May 28, 2003 and was conducted by the University of Illinois School of Public Health's Center for Leadership Development.

The purpose of the workshop was to help consumers develop their leadership skills. Consortium members from all six Illinois projects were in attendance. The conference was well received by the group. The Chicago Healthy Start Consortium appointed its first consumer vice chair as a result of this effort. There are no other consortia serving the same population as Chicago Healthy Start. The Consortium did hold joint meetings with Access Healthy Start on occasion when the consumers requested it.

D. Describe the community's major strengths that have enhanced consortium development.

Response

The community is replete with a cadre of hospitals, social services, community health centers, and consumers that are major stakeholders in Maternal and Child Health programs.

E. Describe any weaknesses and/or barriers that had to be addressed in order for the Consortium to be moved forward.

Response

The Chicago Healthy Start Consortium has not suffered form barriers such as insufficient staff time or other resources, lack of participation by critical stakeholders, irregular attendance, competing agendas and unstable relationships, the political environment, or insufficient commitment of state or community resources.

F. Discuss what activities/strategies were employed to increase resident and consumer participation. How did these change over time?

Response

During the project period the Department utilized childcare, transportation, and other incentives to encourage consumer participation. The most important strategy for ensuring consumer participation is to give them a meaningful role on the Consortium and in the management of the project. The Consortium originally had a standing committee charged with improving consumer participation. This committee, the Consumer Mobilization Committee, was decentralized in order to improve consumer participation. Each Family Center now has its own Consumer Mobilization Committee. A representative from each of these committees participates in meetings of the full Consortium to ensure that the concerns of program consumers are presented.

G. How did you obtain consumer input in the decision-making process?

Response

As outlined in question six, the Department encouraged consumer participation by providing a forum in which consumers could voice their concerns, which were then implemented whenever feasible.

H. How did you utilize the suggestions made by the consumer?

Response

As outlined in answers to questions three and seven, the Department provided consumers with an active voice in the project and continually worked to implement the recommendations from the group.

Coordination with State Title V

A & B

The Department is responsible for both the Title V and Healthy Start grants. Responsibility for the Maternal and Child Health Services Block Grant program (Title V) is placed in the Department's Office of Family Health. Responsibility for the Chicago Healthy Start Initiative is placed in the in the Office of Family Health's Bureau of Maternal and Infant Health. This bureau is also responsible for the Family Case Management, Family Planning, and Perinatal Care programs. Other bureaus in the Office of Family Health are responsible for the Teen Parent Services, Teen Pregnancy Prevention, and Healthy Families Illinois programs. Another bureau in the Division of Community Health Prevention is responsible for the Abstinence-Only Education program. The Chicago Healthy Start Initiative is fully coordinated with the activities of other perinatal care and adolescent health programs at the state level. More information on each of these programs is provided below.

At the local level, each of the Family Centers is also a grantee of the Department's Family Case Management program and Healthy Families Illinois program. Each of the Family Centers also provides or is co-located with an agency that provides services for the WIC program. The Chicago Healthy Start program is thus an integral part of the continuum of perinatal care in the community and closely involved with the State Title V program.

The state Maternal and Child Health programs that are operated by the Family Centers or other agencies in the Project Area include:

- Family Case Management (FCM) is a statewide program that provides service coordination to pregnant women, infants and high-risk children. In SFY'04, 110 Family Case Management agencies were funded by the Department, including local health departments, community-based organizations and federally qualified health centers. Family assessments are conducted and care plans developed on a wide range of needs, including health care, mental health, social health, education,

vocation, child care, transportation, psychosocial, nutrition, environment, development and other services.

- The Teen Parent Services (TPS) Program is offered to young parents (under age 21) who are receiving or applying for TANF or who receive KidCare, Medicaid, or food stamps, and who do not have a high school diploma or GED certificate. TPS assists these young parents to enroll and stay in school, and thus become more self-sufficient for transition form TANF or other public benefits to economic independence programs. Services are provided by 83 contractors (i.e. community-based agencies, educational institutions, and health departments) and by Department staff in two IDHS local offices.

- The Healthy Families Illinois Program seeks to prevent child abuse and neglect through intensive home visits that provide parenting skills education to high-risk families. The purpose of the home visit is to create a relationship with the family that promotes healthy child development, strengthens the parent-child relationship, supports parents as children's first teachers, and helps to reduce family isolation. Services are provided by 51 community-based public health, mental health, child welfare, or social service agencies to particular communities across the state.

- The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) seeks to improve the health status of women, infants, and children; to reduce the incidence of infant mortality, premature births and low birth weight; to promote breastfeeding as the best choice for infant feeding; and to aid in the growth and development of children. The program provides nutrition education and supplemental foods to low-income pregnant, breastfeeding and postpartum women with infants and children up to five years of age who have a medical or nutritional risk.

- The Family Planning Program provides comprehensive family planning services related to the avoidance, achievement, timing, and spacing of pregnancy. Services include client education, counseling, screening, infertility services, pregnancy testing and options counseling, contraceptive methods, and identification and treatment of sexually transmitted diseases. There are 53 agencies statewide, including hospitals, local health departments, single-service family planning centers, and multi-service organizations. Women of childbearing age (including adolescents) with incomes less than 250 percent of the federal poverty level are eligible for family planning services.

- The Abstinence Education Program supports community-based abstinence-until-marriage programs and is funded via Section 510 of Title V. These programs are located in high need areas of the state. Agencies offer in-school and after school programs. The school-based programs are curriculum-driven and taught over periods of up to ten weeks in elementary, middle, and high school settings to students ages ten to 19. Curriculum content and intervention activities conform to

the definition of abstinence education presented in Section 510 of Title V. The after school programs are community-oriented and include motivational activities, seminars, workshops, town hall assemblies, and youth or church group activities. Media and other public and parental activities also occur. Service providers are local health departments, schools, youth-serving community and faith-based organizations, as well as agencies that emphasize prevention and primary services, specifically designed to help adolescents attain self-sufficiency.

- The Teen Pregnancy Prevention Program supports community-based interventions to reduce teenage pregnancy and sexually transmitted diseases. The goals of this program are to enhance collaborative relationships among community partners in order to strengthen teen pregnancy prevention, improve access to health services for adolescents and to increase the role of the schools in improving adolescent health.

- The Perinatal Care Program is a comprehensive statewide system of inpatient services that provides optimal care throughout pregnancy and early infancy in order to improve the health of women and infants. Services are provided to pregnant women who require high-risk delivery and newborn infants who require neonatal intensive care. The length of inpatient perinatal care varies based on the severity of illness and medical complications of the patients. Four levels (capabilities) of perinatal care are well-defined in administrative rules to provide a basis for quality assurance and accountability of hospital-based providers: basic or Level I, intermediate or Level II, specialty or Level II with extended capabilities, and sub-specialty or Level III, with all facilities integrated into networks of care. Each region has a perinatal center that is required to establish and maintain a structure that ensures continuous quality improvement in perinatal care. This structure provides or coordinates an integrated program of quality improvement activities, such as identification of important aspects of perinatal care (e.g. percentage of very low birth weight infants born in a Level III facility of Perinatal Center), collecting data on performance and taking necessary actions to solve problems or otherwise improve the quality and effectiveness of perinatal patient care and the regional system. The perinatal center at Cook County Hospital is located in the Project Area.

C. While there was a budget reduction in some of these programs, there were no significant reductions in service delivery to the Healthy Start population.

Sustainability

A. & B.
The Department required each of its local MCH contractors to enroll as providers in the Medicaid program and to use other private and public payment sources before using the Department's resources to pay for medical care or other reimbursable expenses.

Two of the four local agencies providing Outreach and case management services for the Chicago Healthy Start Initiative are federally funded community health centers and generate most of their operating funds through reimbursement from Illinois' Medicaid program. Further, the healthcare partners for the other two Chicago Healthy Start Family Centers are billing Illinois's Medicaid program sufficiently to sustain the healthcare services they provide.

The Department's in-kind contribution toward the Chicago Healthy Start Initiative can be gauged by the amount of funds awarded to providers in the project area for services related to the Chicago Healthy Start Initiative. The Department's awards for MCH services in the Project Area for FY2004 were presented in the table below.

Amount of Grant Funds Awarded to the Chicago Healthy Start Family Centers and other Community-Based Organizations in the Project Area, by Program: Illinois, SFY'04

Program	Total Amount Rewarded	Healthy Start Providers	Non-Healthy Start Providers
Family Case Management	$4,323,900	$1,659,600	$2,664,300
Teen Parent Services	$595,000	$177,000	$418,000
Healthy Families Illinois	$853,100	$722,600	$130,500
WIC	$1,820,200	$1,168,000	$652,200
Family Planning	$1,073,400	$111,100	$962,300
Abstinence Education	$236,700	$0	$236,700
Teen Pregnancy Prevention	$514,000	$16,000	$498,000
Perinatal Care	$1,613,300	$0	$1,613,300
Total	**$11,292,800**	**$3,854,300**	**$7,438,500**

C. There was no adverse impact to the program due to budget constraints.

E. 1. All of the Family Centers are independent organizations that made their own assessment as to the feasibility of managed care contracting. As described in Section A as an MCH contract the Department required the Family Centers to enroll as providers in the Illinois Medicaid program.

2. Final responsibility for sustaining the CHSI rests with the Department. The direct medical care services provided through the Family Centers are already reimbursed through the Medicaid program or through the federal Section 330 grant to the Community Health Centers. The cost of outreach is already born by the Department through the Family Case Management program. The Illinois Department of Public Aid has recently announced reimbursement for administration of the Edinburgh Postpartum Depression Scale. If federal funds were lost or reduced, case management (including

interconceptional care) could be financed through matching funds from the Medicaid program (as is currently done for the Family Case Management program) if sufficient general revenue funds could be identified (there are no Illinois General Revenue funds available for this purpose at this time). This leaves health education as the only core service for which an alternative funding source cannot be identified.

3. The Family Centers have reported limited problems with barriers.

Section III: **Project Management and Governance**

A. Briefly describe the structure of the project management that was in place for the majority of the project's implementation.

Response

During the majority of the project's implementation the Chicago Healthy Start Initiative was managed by the Department's Office of Family Health. Dr. Stephen Saunders, the Department's Associate Director for Family Health, served as Project Director. Dr. Saunders' appointment expired in April 2005 and was not renewed. The position of Bureau Chief for the Bureau of Maternal and Infant Health was vacated in December 2004. This position was formerly held by Belinda Waller, who served as Assistant Project Director. In addition, the Bureau Chief for Maternal and Child Health is responsible for family planning, family case management, high-risk infant follow-up and Health Works of Illinois. Mr. Jerry Wynn, M.P.H., is the Chicago Healthy Start Project Director.

B. Describe any resources available to the project that proved to be essential for fiscal and program management.

Response

Responsibility for monitoring contracts rests with two organizational units – the Bureau of Community Support Services and the Bureau of Community Health Nursing. The Bureau of Community Support Services has overarching responsibility for program monitoring, support and technical assistance for all DCH&P programs at local agencies. The Bureau of Community Support Services is staffed with a Regional Administrator for each of the Department's five administrative regions. Under the direction of the Regional Administrators, 23 field staff are each responsible for monitoring and technical assistance activities at a small number of local agencies. Four field staff are assigned to Healthy Start agencies. These individuals work in close cooperation with local program staff, staff from the Bureau of Maternal and Infant Health and staff form the Bureau of Community Health Nursing to monitor program activities.

The Bureau of Fiscal Support Services in the Division of Community Health and Prevention accounts for the expenditure of the Division's funds and initiation of payments to contractors. As required by the Fiscal Control and Internal Auditing Act, the Department's Office of Internal Audit conducts audits on a test basis of grants received or made by the Department to determine that such grants are monitored, administered and accounted for in accordance with applicable laws and regulations.

C. What changes in management and governance occurred over time and what prompted these changes?

Response

The two major changes happened toward the end of the project period. Ms. Belinda Waller decided to take early retirement, while Dr. Saunders' appointment was not renewed.

D. Describe what process had to be developed to assure the appropriate distribution of funds and what happened with this process over time?

Response

The Department experienced little if any challenges in this regard. Appropriate distribution of funds was accomplished through the Bureau of Fiscal Services.

E. As the project moves forward with implementation, what additional (non-HS) resources obtained for quality assurance, program monitoring, service utilization, and technical assistance became important, especially as contractors were funded or additional staff members were hired?

Response

As outlined in the response to item B, the Bureau of Community Support Services and the Bureau of Community Health Nursing are examples of non-Healthy Start services that were helpful in the areas of program monitoring and quality assurance in monitoring the subcontractors.

F. To what extent was cultural competency of contractors or project staff an issue? If cultural competency was an issue, how was it addressed and were any noticeable benefits realized?

Response

The utilization of the Family Centers who hired culturally appropriate staff made this a non-issue. The only exception was the hiring of the independent contractor to conduct health education. With the input of the Consortium this component was changed. It appears to be working well.

Section IV: Project Accomplishments – Hamilton Bell

A. Describe each major strategy implemented, with its goals and objectives and accomplishments for this project period. Within the narrative describe in quantitative and qualitative terms the degree of success in achieving the goals and objectives. Describe any barriers that had to be dealt with during implementation and how they were addressed. Summarize all lessons learned. Strategies and goals and objectives that were commonly used across services can be cross-referenced. You may wish to use the Suggested Format in Attachment for this part of your report.

Grantee: Illinois Department of Human Services

Project Period Objectives with a target date of 6/1/05 and 24 performance measures were used to monitor the Project's progress in implementing the Core Services and Core Systems. The DHS Healthy Start Project has made significant progress toward achieving its goals and stated Project Period Objectives. Several of the Project Period Objectives have been achieved and the progress made during 2004 suggest that most if not all of the other Project Period Objectives can be achieved in 2005. The Final Report/Implementation Plan presented below provides the interventions, strategies, and activities and current status of DHS Project Period Objectives in the DHHS recommended format:

Final Report/Implementation Plan

Project Period Objective (to be achieved by 6/25/05)	**Intervention, Strategy and Activities**	**Status/Accomplishments**
Outreach		
Enroll at least 625 Pregnant Women Annually	Outreach is conducted by each Family Center using Family Case Management and WIC. Incentives are used to encourage women to enroll and remain in Program. DHS routinely provided information on "eligible women" to Family Centers. WIC Providers refer pregnant women to Healthy Start. FCM Outreach Staff use a wide array of traditional Outreach methods. Services are delivered through a community driven "one stop shopping" model (i.e., Medical	**This Project Period Objective has been Achieved:** (2003: 665 Enrollees 2004: 673 Enrollees). The Outreach strategy has successfully identified enough hard to reach high risk women to maintain the Program at full caseload. Using FCM Outreach workers avoids duplication of Outreach efforts and integrates the Healthy Start

	Home). Services are provided in a culturally appropriate environment that serves and empowers clients. "Enabling Programs" remove barriers to client enrollment. This includes transportation, child care, translation services, flexible office hours, and Kid Care or SCHIP for Medicaid coverage.	Project with the existing perinatal system. The Healthy Start Project is reaching its intended target population (hard to reach high risk pregnant women). The most common risk factors for 2003-04 were low educational attainment (19.3%), homelessness (18.8%), diseases that effect pregnancy (16.7%), $\geq 4^{th}$ pregnancy or third child expected (12.1%), previous preterm birth (6.6%).
70% of Pregnant Participants Initiate Prenatal Care in the First Trimester	(See Outreach Interventions, Strategies, and Activities listed above).	**This Project Period Objective has been Achieved:** 2003: 82.9% 2004: 82.6%
Case Management		
98% Pregnant and Parenting Participants linked to Medical Home	Each case manager is limited to forty (40) families and each Family Center has funds to support four full time case managers. The Case Management process includes: - Assessments to identify patient needs; - Development of an Individualized Care Plan; - Referral to Providers for needed services; - Advocacy to help surmount access barriers; - Follow up to ensure needed services are received. After their Risk Assessment is completed and entered into Cornerstone, all Healthy Start clients are involved in the development of their services plans. The case manager maintains regular contact with participants and reviews progress toward achievement of goals identified in the Individualized Care Plan. Case managers have face to face contact with their pregnant clients at least twice a month. Half of the case manager's contacts with the	**This Project Period Objective has been Achieved:** 2003: 99.4% 2004: 98.5% Each of the four Family Centers is a federally qualified health center, or linked to a federally qualified health center. The Family Centers provide the Medical Home for all participants. The 2004 data suggests that the Case Management component of the DHS Healthy Start Project has been effective in assisting Healthy Start Participants to negotiate the fragmented health care delivery system and receive the necessary preventative and needed services.

	pregnant participant occur in the participant's home. The case manager uses the DHS Cornerstone System to capture key participant data.	
95% Pregnant Participants Enrolled in WIC	(See Case Management Interventions, Strategies and Activities listed above)	**Significant Progress has been made toward achieving this objective** 2003: 77.4% 2004: 83.4%
65% Pregnant Participants with Adequate Prenatal Care	(See Case Management Interventions, Strategies and Activities listed above)	**Significant Progress has been made toward achieving this objective** 2003: 44.8% 2004: 55.5%
65% Participating Children Current with Well-Child Visits	(See Case Management Interventions, Strategies and Activities listed above)	**This Project Period Objective is expected to be achieved in 2005** 2003: 42.2% 2004: 60.8%
75% Participating Children Current with Immunizations	(See Case Management Interventions, Strategies and Activities listed above)	**This Project Period Objective is expected to be achieved in 2005** 2003: 72.0% 2004: 70.8%
Health Education		
90% of Interconceptional Participants do not smoke during last trimester	Health Education is provided in group settings and is reinforced by the case managers during their frequent interactions. The topics for which Health Education include but are not limited to: Preterm Labor, Normal Infant Growth and Development, Women's Health after Pregnancy, Sexually transmitted diseases (HIV/AIDS), substance abuse prevention, identification of perinatal depression, smoking cessation, parenting skills/discipline, domestic violence/healthy relationships, breast feeding, sudden infant death syndrome. The staffing plan for each Family Center	The data suggests that Healthy Start Participants benefited from the Health Education provided. The Cornerstone Data for 2004 suggested that: - 80.0% of the pregnant participants reported a decrease in drinking alcohol. - 63.4% reported a decrease in smoking. - 70.5% reported use of family planning methods **Limitations:**

	includes a full time Health Educator. The Project conducts an education session at each Consortium meeting in order to inform the residents of the community on key maternal and child health issues. The topics are selected by the consumer members of the Consortium.	The reliability, validity, and completeness of the data currently used to evaluate the Health Education component of the Project is targeted for CQI activity in 2005.
90% of Interconceptional Participants use Family Planning	(See Health Education Interventions, Strategies and Activities listed above)	(See Discussion Above)
Depression Screening and Referral		
100% of Pregnant Participants will be screened for depression	Each of the Family Centers has hired a full time mental health professional to screen participants for perinatal depression and make appropriate referrals. The Project utilizes the Edinburgh Postnatal Depression Scale to screen clients. Clients are screened a minimum of three times for depression: - At Initial Prenatal Care Contact - At Six Weeks Post Partum - Six Months after Delivery Each Family Center uses culturally appropriate staff to conduct depression screening. After a positive screening result, the case manager and the licensed clinical social worker will confer on an appropriate treatment plan for a client. Women who require mental health counseling are either served by the Family Center or referred for mental health counseling, psychotherapy, or psychiatric care. The case managers trace the status and outcome of referrals for mental health services and follow up on incomplete referrals and incomplete appointments.	The Healthy Start Project has historically provided screening for perinatal depression to an average of 640 women per year.

	During the current Project Period, DHS initiated and led several Statewide initiatives related to perinatal depression.	

Section V: Project Impact

A. Systems of Care: Describe how the project has enhanced collaborative interaction among community organizations and services involved in promoting maternal and infant health and social support services.

1. Describe approaches utilized to enhance collaboration.

Response

The project's impact has been achieved through the establishment of the Healthy Start Family Centers. Each of the Family Centers provides one-stop shopping for their clients, which includes both medical and social services. While two of the Family Centers are totally comprehensive medical facilities that are designated as community Federally Funded health centers, two work with hospitals to provide medical services. Additionally, two of the Family Centers established effective referral mechanisms for substance treatment for pregnant/parenting clients. The approach is one of full cooperation among community agencies and the Family Centers in the delivery of services to pregnant and parenting women to achieve optimum perinatal outcomes.

2. Identify the extent to which structured changes, such as procedures or policies, have been established for the purpose of system integration.

Response

This has been achieved through the use of Cornerstone which is the integrated maternal and child health management information system. Cornerstone, as previously described, supports not only Healthy Start, but also the WIC program, the Family Case Management Program, the Illinois Immunization Program, the Perinatal Care and Primary Pediatric Care Programs, Healthy Families of Illinois, and other maternal child health programs.

3. Describe key relationships that have developed as a result of Healthy Start efforts covering the following areas:

a. Relationships among health service agencies and social service agencies and with community-based organizations;
b. Relationships that focus on involvement of consumers and/or community leaders (who are not employed by a health or social services agency) with any of the agencies/organizations listed above or any additional agencies.

Response

As previously described, the establishment of the Family Centers has encouraged relationships with both health and social service agencies to ensure a comprehensive service delivery system to clients within the Healthy Start Project Area. This includes substance abuse services, mental health, HIV/AIDS, and other services previously mentioned. In regards to consumers and/or community leaders, the project has involved its consumers on the project at the Consortium level to get input on means to improve the project. This effort has proven effective. The project hosted a major forum on leadership

development that resulted in consumers taking leadership roles on the Consortium as well as proactive roles in their respective communities and in some instances becoming registered voters for the first time.

4. Describe the impact that your HS project has had on the comprehensiveness of services, particularly in the following areas:

   a. Eligibility and intake requirements for health or social services.

Response

During the project period Chicago Healthy Start has contributed to streamlining the intake process. Potential clients are entered into Chicago Family Case Management and given a comprehensive risk assessment. As part of this risk assessment women are screened and referred to the appropriate level of care.

   b. Barriers to access and service utilization and community awareness of services.

Response

The Chicago Healthy Start Family Centers are designed to remove barriers to needed services. Healthy Start's core services are provided in the Family Centers along with WIC services and comprehensive primary medical care. Erie Family Health Center, which serves a large number of undocumented residents, reported that a loss of Medicaid coverage six weeks postpartum is a barrier to care for women. In response, the Department developed the Illinois Healthy Women Program. It provides voluntary and confidential family planning and reproductive health care at no cost to women who lose regular IDPA medical benefits.

   c. Care coordination, including descriptions of mechanisms implemented to assure continuity of care, quality improvement and follow-up system(s) for client referrals.

Response

Again the Family Centers served as the nucleus of the service delivery system for those women who enrolled in Chicago Healthy Start. To assure continuity of care the case manager served as the clients' ongoing contact for follow-up of referrals, which are documented on Cornerstone. In terms of quality improvement, the mechanisms include the Data and Evaluation Committee of the Consortium, which reviews indicators on a quarterly basis and makes recommendations for improvement. Additionally, Chicago Healthy Start uses case conferences for supervision, coordination of services, and quality improvement. These conferences occur at the Family Center and are interdisciplinary – medical providers, case management staff, and supervisors are in attendance. Usually five cases are presented at each session. The frequency of case conferences varies among the Family Centers, although they are held at least once a month.

   d. Efficiency of agency records systems and sharing of data across providers (within the confines of confidentiality rules) to reduce the need for repetition.

Response

As previously described, the Department used Cornerstone to support Chicago Healthy Start's Case Management Function. Cornerstone is a comprehensive MCH case management system that was designed to avoid unnecessary duplication. The Department follows strict guidelines regarding confidentiality rules and a paper consent form is reviewed with all clients. A client signature is obtained before any data entry is initiated.

5. Describe the impact on enhancing client participation in evaluation of service provision in the following areas:

   a. Provider responsibility in maintaining client participation in the system and provider sensitivity to cultural, linguistic and gender (especially male) needs of the community.

Response

One of the key components to the success of the Chicago Healthy Start Family Centers is to ensure client participation. This is achieved through the use of culturally appropriate staff at the Family Centers. For example, at Erie a Latino population is served. To be effective the service delivery system must address the male population not only in the linguistic area, but culturally as well so as to include males in the case management delivery system. Another agency, Henry Booth, has seen growth in the Asian population. Like the Latino population the male is seen as being the leader of the family. This Family Center also utilizes culturally appropriate staff and addresses the role of the male or significant other in the provision of case management services.

   b. Consumer participation in developing assessment and intervention mechanisms and tools to serve perinatal women and/or infants and the extent of implementation and utilization of these tools or mechanisms.

Response

The Department developed a one-day didactic session on Cornerstone for consumers as a result of a request of the Consumer Mobilization Committee. The session covered all aspects of the system and gave the clients the opportunity to get an overview of all the case management programs, including WIC and Healthy Start. The presentation was well received by the group.

B. Impact to the Community

Describe the impact the project has had on developing and empowering the community at a minimum in the following areas:

1. Residents' knowledge of resource/service availability, location and how to access these resources.

Response

Multiple components of Chicago Healthy Start project have facilitated success on this end. First, through the Chicago Healthy Start Family Centers and in particular the Case Manager, clients are provided with a knowledge of how to access resources including WIC, medical care, transportation and other key services. Second, the Health Education component provides the consumers with information on breast-feeding, HIV and sexually transmitted infections, and the risk of pre-term labor. Third, through the Interconceptional Case Management Component, clients develop goals on employment, housing and education.

The cumulative impact of these areas has enhanced the clients' ability to become self-sufficient and lead to improved perinatal outcomes.

2. Consumer participation in establishing or changing standards and/or policies of participating service providers and local governments that affect the health or welfare of the community and have an impact on infant mortality reduction.

Response

As mentioned previously, consumers were key in helping revise the Health Education Component. The use of consumer surveys has indicated overall that they are satisfied with the quality of services and the manner in which they are rendered in the community. The results of the Fetal Infant Mortality Review Project indicate the need to address issues in the academic medical centers. One major issue is that clients are not content to see different medical providers when they come for prenatal visits. This is an issue the Department will work on to change during the next funding cycle.

3. Community experience in working with divergent opinions, resolving conflicts, and team building activities.

Response

The project has been successful at implementing team building activities and resolving conflicts in the following manner. On May 28, 2003, the Leadership Forum conducted by the University of Illinois addressed this problem. The meeting provided a session on medication and negotiation. There was also a session on developing an atmosphere of trust, mutual support, and mentoring others. Consumers were able to utilize these skills on the Consumer Mobilization Committee and the Interconception Care Groups established in each Family Center.

4. Creation of jobs within the community.

Response

Where possible the Family Centers hired community residents in paraprofessional roles. The Family Centers were helpful in helping the clients become job-ready and obtain employment in other areas.

C. Impact on State

As previously mentioned, the Department is responsible for both the Title V and Healthy Start grants. Responsibility for the Maternal and Child Health Services Block Grant program (Title V) is place in the Department's Office of Family Health; responsibility for the Chicago Healthy Start Initiative is placed in the Office of Family Health's bureau of Maternal and Infant Health. This Bureau is also responsible for the Family Case Management, Family Planning, HealthWorks of Illinois, High-Risk Infant Follow-Up, Pediatric Primary Care and Perinatal Care programs. The Office of Family Health is also responsible for the administration of the WIC (Special Supplemental Nutrition Program for Women, Infants and Children), Teen Parent Services, Parents Too Soon, Healthy Families Illinois and Teen Pregnancy Prevention programs. The Chicago Healthy Start Initiative is fully coordinated with the activities of other perinatal care programs at the state level.

This proved to be a tremendous advantage for the Chicago Healthy Start project. The Department worked to ensure that relevant programs such as WIC and Healthy Families Illinois were all at the Healthy Start Family Centers and that the clients enrolled in the project got the full level of services as part of the Comprehensive System of Perinatal Care. Additionally, the four Chicago Healthy Start Family Centers were designated as KidCare Application Agents in 2000. (Illinois markets both the Medicaid program and State Child Health Insurance Program [SCHIP] under the name "KidCare.") The family Centers assist parents of potentially eligible children to complete a KidCare application. Family Center staff have received training on the application process from the Illinois Department of Public Aid.

As enrolled providers in the KidCare program, each of the Family Centers receives third-party reimbursement for the services it provides to each eligible woman and child. Further, Illinois has increased the Medicaid income eligibility threshold for pregnant women to 200 percent of the federal poverty level. Virtually every pregnant woman and every infant in the project area is potentially for KidCare.

Another benefit as described earlier in the report was Chicago Healthy Start was in a leadership role in providing services in the area of screening for Perinatal Depression. The Department staff was able to make both short-term and long-term recommendations to improve services statewide. The Department also worked closely with Public Aid in establishing a payment mechanism for medical providers to get reimbursement for screenings using the Edinburgh Screening Instrument.

The entire relationship of having the Department serve as both the Title V Grantee and the Healthy Start Grantee has been beneficial in terms of comprehensive service delivery.

D. Local Government

There have been few if any barriers that impacted on service delivery.

E. Lessons Learned

During the project period the Department served as convenor of the Illinois Healthy Start Programs Partnership. This group included the five other federal grantees in the state. The only lesson to be conveyed to others is to establish a good working relationship with the Title V Maternal and Child Health Agency.

Section VI: Local Evaluation

Using the suggested format in Attachment C, submit a copy of the Healthy Start Local Evaluation Report for each local evaluation conducted. Instructions pertaining to this report are provided in Attachment B.

Section I. INTRODUCTION

Local Evaluation Component

A. Discuss the impetus for the local evaluation. How was the local evaluation designed? Were project staff involved in conducting the local evaluation or was the evaluation contracted out? If contracted out, identify the name of the contractor.

The impetus for the Local Evaluation was twofold:

1. HRSA strongly encouraged funded Healthy Start Projects to conduct a Local Evaluation that was independent but compatible with the National Efforts to evaluate the Performance and Effectiveness of Healthy Start Projects. According to Federal Guidance, a Healthy Start Project lacking a complete and well conceived Evaluation Protocol may not be funded.

2. DHS valued an independent review of the Healthy Start Project and the development of a well designed and scientifically sound Evaluation Plan. The Plan had to be capable of demonstrating and documenting measurable progress toward achieving stated objectives and include a Continuous Quality Improvement Process.

DHS held that the Evaluation Plan and the measurement of progress should be focused through empirically defined, outcome-oriented objectives designed to monitor the "performance" and "effectiveness" of the DHS Healthy Start Project in implementation of the "required components" of the Project and their impact on the health status of the target population. The Evaluation Plan was based on a clear rationale tied to meeting the identified needs of the target population.

The Project's local evaluation was designed to be a combined Outcome and Process Evaluation intended to assess both the impact of the Healthy Start interventions on natality and mortality among program participants and racial disparity in the targeted communities. The plan was developed by Hamilton•Bell Associates, a Chicago management and health care consulting firm with extensive experience in maternal and child health.

As local evaluator for the DHS Healthy Start Project, HBA facilitated a process to develop an Evaluation Plan that met DHS expectations, and was in compliance with HRSA Guidance. This Evaluation Plan was developed under the leadership of the Local Evaluator (HBA), with input from DHS Leadership, Healthy Start Project Staff, and members of the Consortium. The Evaluation Plan has a four part focus:

- Project/Agency Performance in Implementing Core Services;
- Project Effectiveness in Improving the Health Status of mothers and infants;
- Health System Interface/Integration (i.e., screening and intervention for depression); and
- Racial Disparity in the Project Area.

B. *Present a brief history of the local evaluation and describe all components. Was each of these components the subject of an evaluation study? Were some components of the evaluation added, dropped or modified? Please explain.*

The Evaluation Plan was developed in collaboration with DHS Leadership, the participating Agencies, and the Consortium. The Plan has the following three components:

- *Project Performance in Implementation of Core Services;*
- *Project Performance in Implementation of Core Systems*
- *Project Effectiveness in Improving Health Status and Racial Disparities*

The performance and accomplishments of the DHS Healthy Start Program was measured both quantitatively and qualitatively. At the *client level* the impact is measured in incremental improvements in birth outcomes, health behavior and client knowledge and perceptions. At the *service delivery level,* impact is measured by the Project's performance in the implementation of efficient and effective approaches to deliver the five (5) Core Services and the four (4) Core Systems. At the *community level* a longitudinal comparison is used to measure changes in the Healthy Start target population residing in the six (6) Community Areas in Chicago that comprise the Project Area. Changes in Health Status among to Project Area residents will be compared to changes among residents in two reference areas (City of Chicago and State of Illinois) over time.

The evaluation of the DHS Healthy Start Project focused on achievement of a defined set of objectives for the project period and calendar year. The Performance Objectives were organized and linked to monitoring progress in Agency implementation of the *Core Services* and *Core Systems* and the overall Project Effectiveness in improving Health Status among participants.

Most project objectives were measured at the client level through the DHS Healthy Start Information System. At the community level, Illinois Vital Records were used to measure changes in perinatal health status indicators. Special surveys and other primary data collection methods will be used to examine client satisfaction.

Qualitative measures used in the evaluation included a *Healthy Start Participant Satisfaction Survey* designed to help DHS and the Consortium determine the level of satisfaction that participants have with the delivery of services through the Healthy Start Project. The survey was conducted annually.

The DHS Healthy Start Project institutionalized a Continuous Quality Improvement Program. Routine monitoring of Performance Measures that finds that "expectations" are not being met, will result in a more focused review to identify and resolve issues/barriers to meeting stated objectives. The CQI program involved all stakeholders.

A Healthy Start CQI Committee consisting of the Local Evaluator, the Project Director, representation from all participating Agencies, and MCH nurses and Case Managers serving the Target Areas, met on a quarterly basis to review HBA findings and recommendations for seeking improvement and conducting more "Focused Review" which subsequently led to changes in policies and/or implementation processes or procedures. The "Focused Reviews" that were approved by the CQI Committee would be carried out by all four (4) participating Agencies or one specific Agency that had been identified as an *"outlier"* on a specific performance measure. These Focused Reviews provided the context and resources necessary to complete an "Evaluation Study" (See Appendix 2-4).

As part of the "Outreach" Evaluation, HBA used Cornerstone Data on participants to develop statistical profiles that provide a *Demographic Profile* of all Healthy Start participants and a *Risk Profile* of pregnant participants.

C. Discuss the type of study (e.g., formative, process, outcome, SEE DEFINITIONS), and the involvement of the community and the consortia in conducting the evaluation.

HBA's Plan for the Local Evaluation calls for a three-phase implementation process. The three phases of the evaluation are the *Formative Phase*, the *Process Phase* and the *Outcome Phase*. The tasks accomplished in each of these phases to date are briefly described below.

Formative Phase: Upon engagement as the independent "Local Evaluator," for the DHS Healthy Start Project, HBA initiated the *"Formative Phase"* of the Local Evaluation. During the *Formative Phase, HBA* played a leadership role in designing and implementing a process to bring DHS and the participating Agencies together in the collaborative development of an Evaluation Plan for the Project. This Plan was ultimately reviewed and accepted by the Consortium and approved by DHHS.

During this phase, HBA also assisted DHS efforts to redesign the "Core Interventions" to comply with revised HRSA Guidance. HBA facilitated a process of Agency and Evaluator feedback that helped DHS confirm *what the Participating Healthy Start Agencies were doing to implement the Core Services and Core Interventions required*. The Formative Evaluation identified the DHS policies and implementation processes that needed to be "synchronized" in order to be effective.

During the *Formative Phase,* HBA and DHS worked with the participating Agencies to examine, design, and implement modifications to "implementation processes" that included:

- Outreach Activities;
- Risk Assessments;

- Use of Incentives;
- Staffing Patterns and Retention;
- Interface with Family Case Management;
- Cornerstone Data Collection Procedures; and
- Communication between/among Participating Agencies

Process Phase: The *Process Phase* began when DHS and participating Agencies "signed-off" on the Healthy Start Evaluation Plan. The Evaluation Plan included an empirically based set of Project Period Objectives and 24 performance measures used to monitor Agency Performance in implementing each of the Core Services and Core Systems required by HRSA. The *Process Phase* was designed to monitor how the program was being implemented by participating Agencies. During the *Process Phase*, the evaluation was primarily focused on monitoring and evaluating participating Agencies' progress toward meeting objectives as defined in the Evaluation Plan as well as other DHS expectations.

During the *Process Phase*, HBA designed, developed and distributed a series of Standard Reports (based on DHS Cornerstone Data) that were used to monitor Agency performance and progress toward meeting objectives for each of the Core Services. These Standard Reports were generated and distributed on a quarterly and year-to-date basis. Progress toward meeting objectives was measured at the Project, Agency, and Clinic levels.

Additionally, HBA prepared and presented quarterly analyses by Project and Agency that summarized and updated:

1. The Demographic Profiles of *Pregnant* and *Interconceptional Participants*;
2. Risk Profiles of newly enrolled *Pregnant Participants;* and
3. Current Status of Agency Performance in implementing Core Services for all *Pregnant*, *Interconceptional* and *Child Participants*.

These quarterly analyses also highlighted the specific performance measures that were not being met by one or more participating Agencies. This information became the basis of CQI activity leading to changes in policy and/or implementation processes and ultimately improvement in the performance measure.

During this Phase, HBA played a leadership role in the design and institutionalization of the methodology for ongoing review and evaluation of key implementation processes. HBA designed and institutionalized a Continuous Quality Improvement Program (CQI). A CQI Committee provided the structure for review and modification of Agency activities. The CQI Committee included the Project Director, Representatives from participating Agencies, Nursing Staff responsible for oversight of Case Management Agencies and data entry into Cornerstone, and the Local Evaluator.

The Healthy Start CQI Committee met on a quarterly basis to review HBA findings and recommendations for seeking improvement and conducting more "Focused Review" which subsequently led to changes in policies and/or implementation processes or procedures. The "Focused Reviews" that were approved by the CQI Committee would be carried out by all four

(4) participating Agencies or one specific Agency that had been identified as an *"outlier"* on a specific performance measure.
In summary, the CQI program has been effective in identifying and resolving barriers to Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., appropriate documentation of events and data entry into Cornerstone).

Outcome Phase: The Healthy Start Project has now entered the *Outcome Phase* of the evaluation. The *Outcome Phase* is designed to look at longer-term outcomes. The *Outcome Phase* of the evaluation cannot be finalized until vital records data used to track health status indicators for not only the *Target Population* but also *Project Participants* is available through at least 2004. Currently, vital records data through 2002 is available for only the *Target Population*.

The *Outcome Phase* will determine if the Healthy Start Project had an "impact" on the health status of the population served. The Evaluation Plan identified a select set of health status and racial disparity indicators which will ultimately be used to determine the "Effectiveness" of the Project.

At this point in time, HBA has completed a partial analysis of Project Effectiveness. Using vital records data, the "impact" that the Healthy Start Project has had on birth weight and mortality in the *Target Population* (i.e., at risk women in Target Areas) through 2002 has been determined. However, the more relevant component of the "effectiveness" evaluation cannot be completed since data on birth weight and mortality for *Healthy Start Participants* is not currently available.

Key Questions/Hypotheses

Discuss key questions and hypotheses the local evaluation addressed.

The DHS Healthy Start Project Evaluation was designed to answer a well-defined set of general and specific questions. The general questions the DHS Healthy Start Evaluation will seek to answer over the life of the project are:

1. *To what extent did the DHS Healthy Start project achieve its process (i.e., performance) and outcome (i.e., health status) objectives?*

2. *Is there an association between receiving Healthy Start services (i.e., the five Core Services related to prenatal, infant and interconceptional care) and an improvement in birth outcomes, perinatal, and infant mortality?*

3. *To what extent did the Healthy Start Project act as a catalyst for policy changes and systems interface/integration with the larger Perinatal System?*

4. *To what extent has the racial disparity in the DHS Healthy Start Project Area been addressed among key MCH Indicators?*

A more detailed set of questions to be answered include but are not limited to:

- *Has the rate of infant, neonatal, or postneonatal mortality decreased in the Healthy Start Project area? Has there been a reduction in racial disparity?*

- *How have the infant, neonatal and postneonatal mortality rates for the Project Areas changed (increase or decrease) in relation to the State of Illinois and the City of Chicago? Has there been a reduction in racial disparity?*

- *How much has the change in neonatal versus postneonatal mortality contributed to the change in infant mortality that occurred in the Project Areas?*
- *Has the change (increase or decrease) in infant mortality varied in the targeted community areas?*

- *Has the rate of VLBW (under 1500 grams) or LBW (under 2500 grams) decreased in the Healthy Start Project Areas? Has there been a reduction in racial disparity?*

- *How have the VLBW and LBW rates for the Project Areas changed (increase or decrease) in relation to the State of Illinois and the City of Chicago?*

- *Has the change (increase or decrease) in VLBW or LBW varied by race within the targeted community areas?*

- *Has the rate of low prenatal care, birth to teens and births to single moms decreased in the Healthy Start Project Areas? Has there been a reduction in racial disparity?*

Section II. PROCESS

A. Discuss the procedures for conducting the local evaluation. Describe the role of the community or consortium in conducting the evaluation. Discuss the methodology (ies) in the local evaluation (e.g., case study of five agencies, secondary analysis of vital records data, pre and post interviews with women participating in health education, etc.). Describe the sampling design, if any and any comparison or control groups used.

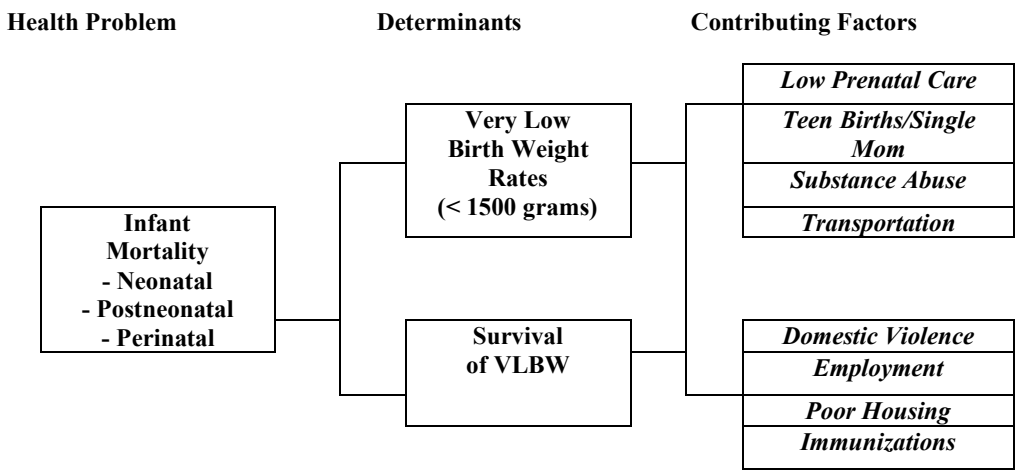
1. Framework for Local Evaluation:

The framework for the Healthy Start Local Evaluation was based on a model that was developed by CDC and has proven to be "user friendly" in that it encourages participation of all key actors (e.g., health professionals, health care providers and health care consumers) in the evaluation. CDC's Public Health Practice Office originally developed the *Health Problem Analysis Model* in 1991. HBA, as Local Evaluator for the Healthy Start Project, facilitated the introduction and use of the Health Problem Analysis as a framework for evaluation. This framework will be used as a structure for sharing information with the Consortium and other consumers while soliciting input on local contributing factors that impact on the access and availability of services needed to improve perinatal outcomes and reduce infant mortality. The Project utilized this framework to facilitate an understanding and involvement of all key actors (e.g., Consortium), in the design of the evaluation.

The chart on the following page illustrates the *Health Problem Analysis Model* used for the Healthy Start Evaluation. The model identifies three levels of assessment: *health problem, determinants* and *contributing factors.* Outcomes relate to the level of health problems and are specified in terms of measures of health status, such as mortality, morbidity and disability rates. Each health problem has one or more determinants which can be defined as direct causes or risk factors which, based on scientific evidence or theory, are thought to directly influence the level of a specific health problem. Low birth weight is a prime example of a determinant for the health problem of neonatal mortality.

The ability to analyze health problems (e.g., infant mortality) hinges on the identification of risk factors and pathways of causation. This type of analysis is necessary in order to make appropriate programmatic decisions and identify specific actions that can address factors that directly relate to the health problem under review. First, however, it is necessary to define the *health problem* itself. In this analysis, preventable infant mortality is the problem and can be measured by a number of *health status indicators*. These indicators include infant, neonatal, post-neonatal, perinatal, and fetal mortality rates.

HEALTH PROBLEM ANALYSIS
(Simplified Example)



The Health Problem Analysis requires that health problems be clearly specified and that all pertinent determinants and their contributing factors be identified. With health problems as complex as perinatal health outcomes, this can be an extensive undertaking.

This component of the evaluation will provide information on health status indicators and its determinants. The analytic and data gathering process to be utilized should yield a priority list of contributing factors (direct and indirect) as identified by the Consortium, professional staff, and consumers.

2. Methodology for Evaluation of Project Effectiveness

Using information obtained from the Illinois Department of Public Health and the Illinois Department of Human Services, an analysis of key indicators of maternal and child health was completed by Hamilton•Bell Associates. The poor health status of mothers and infants in the Chicago Healthy Start Project Area was empirically defined. Data/information extracted from vital records (birth and death certificates) filed with the State Registrar was used:

1. To compare MCH health status indicators, their determinants and contributing factors for residents in the Project Area to residents of the State of Illinois and City of Chicago (external reference).

2. To define and compare the racial disparity that exists in MCH health status indicators, as well as their determinants and contributing factors for residents in the Project Area (internal reference).

For this component of the evaluation, a set of "questions to be answered" were developed. The answers to these questions required a review and comparison of the changes in selected indicators over the study period and a comparison between the Healthy Start Project Area, the City of Chicago, and the State of Illinois. The source of information used to address these questions was vital records filed with the Illinois Department of Public Health for the Project Period.

A longitudinal comparison was used to measure and observe changes in selected mortality and natality indicators over time within the six community areas in Chicago that comprise the Project Area. The changes in the Healthy Start Project Area were also compared to those changes that occurred in the City of Chicago and the State of Illinois during the same time period. The Illinois Department of Public Health performs quality assurance activities on Vital Records. The Department uses edits to measure, monitor and seek to improve the accuracy, completeness and reliability of the information captured on live birth, death and stillbirth records. The reliability and validity of the fields of information available from these vital records vary widely according to both IDPH experience and the research literature. Based on discussions with key staff at IDPH and DHS and their knowledge of the relevant research, the specific fields of information used in this analysis are considered to be among those that are substantially valid and reliable.

Due to the rarity of events being measured (e.g., infant mortality) and the resulting small numbers involved in rate calculations at the Community Area level, three year moving averages were used rather than single year rates. This methodology provides greater stability to the rates and limits the spurious variability introduced by small number calculations for individual years. All rates based on less than ten (10) events in the numerator or one hundred (100) events in the

denominator are often suppressed in this type of analysis. However, since three-year moving averages were used to calculate rates, the rates have been provided but caution was used in the interpretation and findings.

For tests of significant difference in rates over time within the Project Area, a binomial approximation to the normal distribution was used. For comparison of rates within areas over time, the difference between the probability at base line and at the end of the study period was measured and a confidence interval was calculated. The confidence interval was the used to determine whether the difference in rates was statistically significant given the sample size, the magnitude of the difference and a 95% level of confidence.

B. Identify and describe the data sources.

- The DHS Cornerstone System provided the data on Healthy Start Participants and was used to monitor, evaluate and improve Agency Performance in implementing the Core Services.

- Vital Records Data was used to evaluate the "Effectiveness" of the Healthy Start Project in improving the Health Status of Healthy Start Participants as well as the Health Status of the Target Population.

C. What measures were used? Describe any instruments used.

Below is a list of the Measures that were used in the Evaluation of *Project Performance* in implementing Core Services and Core Systems and the overall *Effectiveness of the Project*:

A. Project Performance in Implementing Core Services

1. Outreach and Recruitment
- Number of high risk pregnant women identified from target area
- Percent high risk pregnant women who initiate prenatal care in 1st trimester

2. Case Management
- Percent of eligible high-risk pregnant/postpartum women/infants enrolled
- Percent with adequate prenatal care (Kessner Index)
- Percent of high-risk pregnant women linked to a "medical home"
- Percent of high-risk pregnant women enrolled in WIC
- Percent of children (0 - 2) linked with a "medical home"
- Percent of referrals made and kept for Pregnant, Child, Interconceptional Participants
- Percent of participants who complete initial postpartum visit
- Children (0 - 2) up-to-date with immunizations
- Children (0 - 2) up-to-date with EPSDT exams

3. Health Education

- Pregnant participants self-reporting reduction/cessation in smoking during pregnancy
- Pregnant participants self-reporting reduction/cessation of substance abuse during pregnancy
- Interconceptional participants that self-report breast feeding of infants
- Interconceptional participants that self-report use of Family Planning services
- Interconceptional participants with more than 18 months between pregnancies

4. High Risk Interconceptional Care
- Percent of Pregnant participants who completed a post partum visit.
- Percentage of high risk participating women who receive interconceptional services
- Percentage of Interconceptional women linked with a medical home
- Reduce the proportion of pregnancies occurring within 24 months of a previous birth
- Increase the percentage of women receiving family planning services in the post-partum period.

5. Perinatal Depression
- Number and percent of Healthy Start participants who deliver and are screened for depression
- Number and percent of Healthy Start Participants who are screened for depression (EPDS) and are referred for diagnosis/treatment.
- Number and percent of Healthy Start participants who were referred for and received treatment/consultation for depression.

B. Project Performance in Implementing Core Systems

1. Local Health Systems Action Plan
- Extent to which objectives of the local health action plans are accomplished.
- Extent to which Healthy Start Core Services/Systems are integrated/interfaced with the local MCH Health Service Delivery System.

2. Collaboration with Title V
- Participation in Title V Needs Assessment
- Interface with Title V Programs and Services
- Exchange of Data and Information

3. Consortium
- Percent of consumers participating in Consortium activities
- Increase in capacity of Consortium members (training efforts)

4. Sustainability/Administration/Management
- Efficient use of resources (i.e., staff and dollars)
- Modification/Improvement in Interventions based on Lessons Learned
- Development of Sustainability Plan

- Dissemination of Evaluation Findings and Conclusions

C. Project Effectiveness Toward Improving Health Status and Racial Disparity

To measure Program Effectiveness in improving "Health Status" among residents of the target population, a longitudinal comparison was used to measure and observe changes in selected MCH Indicators within each of the targeted Communities and compare to changes that occurred in 2 reference areas (City of Chicago and State of Illinois).
The set of indicators that were used to monitor **Project Effectiveness** included:

- Infant, neonatal and postneonatal mortality rate in the Project Area
- Impact on racial disparity for perinatal outcomes in the Project Area
- Percent of low birth weight (LBW) and very low birth weight infants (VLBW)

Section III. FINDINGS/DISCUSSION

*Present the **findings** of your local evaluation including a discussion of any methodological **limitations** of the evaluation (e.g., completeness and quality of data, and response rates to survey instruments).*

1. Current Status of DHS Healthy Start Project Period Objectives

Below is a table that is intended to succinctly identify the findings and limitations of the Local Evaluation. The table organizes the findings and limitations by Project Period Objectives.

Project Period Objective (to be achieved by 6/25/05)	**Core Service**	**Findings and Limitations**
Pregnant Participants		
Enroll an average of 625 hard to reach high risk women annually	Outreach	**Findings:** A review of the data in Appendix 2 finds that 665 "hard to reach, high risk" pregnant women were enrolled in 2003 and 673 were enrolled in 2004. The DHS Healthy Start Project has met the target level for this Project Period Objective. **Limitations:** None
70% of Pregnant Participants Initiate Prenatal Care in the First Trimester	Outreach	**Findings:** A review of the data in Appendix 2 will find that the Healthy Start Project has achieved the target level for this Project Period Objective. Approximately 82% of

		the *Pregnant Participants* initiated their prenatal care in the first trimester in both 2003 and 2004. A review of Agency Performance finds that three (3) of the four Agencies exceeded the target level (70%) for this Project Period Objective and one Agency (Winfield Moody) is at 69%. **Limitations:** None
98% Pregnant/Parenting Participants linked to Medical Home	Case Management	**Findings:** A review of the data in Appendix 4, will find that DHS has achieved the target level for this Project Period Objective. In 2004, 98.5% of *Pregnant Participants* and 99.1% of Interconceptional (e.g., parenting) Participants were linked to a *"medical home."* **Limitations:** None
95% Pregnant Participants Enrolled in WIC	Case Management	**Findings:** In 2003, 77.4% of the *Pregnant Participants* were enrolled in WIC and this improved to 83.4% in 2004. Agency-specific review of this performance measure finds that no Agency has achieved the target level (95%) for this Project Period Objective. The percentage of *Pregnant Participants* enrolled in WIC in 2004, varied from a low of 79.5% (Winfield Moody) to a high of 86.2% (West Side Future)-(See Appendix 3). **Limitations:** None
65% Pregnant Participants with Adequate Prenatal Care	Case Management	**Findings:** This measure became the focus of CQI activity during 2004. As a result, the percentage of pregnant participants with Adequate Prenatal Care increased from 44.8% in 2003, to 55.5% in 2004. Only one Agency (Erie Family Health Center) has achieved the target level. This Performance

		Measure will continue to be an area for CQI activity in 2005 (See Appendix 3). **Limitations:** None
Interconceptional Participants		
90% of Interconceptional Participants do not smoke during last trimester	Health Education	The data suggests that Healthy Start Participants benefited from the Health Education provided. The Cornerstone Data for 2004 suggested that: - 80.0% of the pregnant participants reported a decrease in drinking alcohol. - 63.4% reported a decrease in smoking. - 70.5% reported use of family planning methods (See Appendix 3). **Limitations:** The reliability, validity, and completeness of the data currently used to evaluate the Health Education component of the Project is targeted for CQI activity in 2005.
90% of Interconceptional Participants use Family Planning	Health Education	(See Discussion Above)

Child Participants		
65% Participating Children Current with Well-Child Visits	Case Management	**Findings:** This Performance Measure became the focus of CQI activity in 2004. As a result, the percentage of children that were current with Well-Child Exams increased from 42.2% in 2003, to 60.8% in 2004. Given the improvement that DHS has made in the interface between IDPA Paid Claims and Cornerstone, HBA anticipates that the Healthy Start Project is well positioned to reach the target level (65%) for this Project Period Objective. This performance measure will continue to be targeted for CQI activity in 2005 (see Appendix 3). **Limitations:** None
75% Participating Children Current with Immunizations	Case Management	**Findings:** A review of the data in Appendix 3, finds that the target level for this Project Period Objective has not been achieved. However, it is very likely to be achieved by 6/1/2005. Approximately 71% of all participating children were current with immunizations in 2003 and 2004. An Agency-specific review finds that two of the Agencies, namely Erie Family Health Center (79.8%) and Henry Booth House (78.1%) have achieved the Project Period Objective. HBA finds that the Agencies in the Project are well positioned to achieve the Project Period Objective for this performance measure. **Limitations:** None

2. Findings of Local Evaluator

As an independent Local Evaluator for the Healthy Start Project, Hamilton•Bell Associates found that:

1. *The DHS Healthy Start Project is effective*. An analysis of data for 2000-2002 finds improvement in virtually all key Maternal and Child Health Indicators (including infant mortality and very low birth weight) in the Target Population.

2. *The DHS Healthy Start Project is "efficient*." The Project was designed and implemented to successfully interface and complement other Title V programs. Using Family Case Management outreach workers to provide "Outreach" avoids duplication of services and a more effective interface of the Healthy Start Project with the existing Perinatal Service Delivery System.

3. *The DHS Healthy Start Project finds and enrolls the "hard to reach, high risk" pregnant population in the Targeted Communities*. This can be documented by the *risk profile* of over 2,000 "hard to reach, high risk" *Pregnant Participants* that have been served by the Project.

4. *The DHS Healthy Start Project is at full caseload and will enroll in excess of 2500 "hard to reach, high risk" pregnant women over the life of the Project*.

5. *The DHS Healthy Start Project has a CQI Program that has been effective in identifying and resolving barriers to improving Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., data entry into Cornerstone)*.

6. *The DHS Healthy Start Project has made progress toward achieving its stated Project Period Objectives*. Three of the nine (9) Project Period Objectives have been achieved and the progress made between 2003 and 2004 suggests that most if not all of the other Project Period Objectives can be achieved in 2005.

7. *DHS and the participating Agencies have successfully collaborated in the identification of areas needing improvement in 2005*.

Section IV. RECOMMENDATIONS

*A. Present all **recommendations** that stemmed from the local evaluation. Please be sure to include policy, program, practice as well as other recommendations.*

Recommendation # 1: DHS should expand CQI Activities to include Data Access, Data Validity, and Data Reliability Issues

The DHS Healthy Start Project can document a CQI Program that has been effective in identifying and resolving barriers to improving Agency performance in implementing the Core

Services and meeting other DHS expectations (i.e., data entry into Cornerstone). As a result of the efforts of the CQI Committee and the corrective actions taken by participating Agencies:

1. The data available from Risk Assessments was more complete and reliable;
2. The percentage of *Child Participants* that were current with Well-Child Exams increased from 42.2% in 2003, to 60.8% in 2004.
3. The percentage of *Pregnant Participants* with "Adequate Prenatal Care" increased from 44.8% in 2003 to 55.4% in 2004.

During FY 05 the Local Evaluator and the CQI Committee recommended that DHS expand Focused Reviews and CQI activity beyond program issues related to implementation of the core services. The CQI Committee and HBA would like to expand CQI into the following areas which are targeted for improvement.

A. Data Access Issues:
- Timely access to accurate birth data for residents of the Project Areas
- Timely access to accurate mortality data for Project Area residents

B. Data Reliability/Validity Issues:
- Birth Weight and Mortality of Participants*
- Ethnicity of Participants,
- Performance Data for the Evaluation of Health Education Activities

C. Programmatic Issues:
- Adequacy of Prenatal Care
- Well-Child Exams
- Completed Post-Partum Visits
- "Medical Home" for Child Participants

Recommendation # 2: Redesign and Improve Annual Patient Satisfaction Survey.

All Agencies should actively participate in efforts to revise and improve the Patient Satisfaction Survey for Healthy Start clients. The Agencies, DHS staff (i.e., nurses), and HBA have agreed to review the existing Patient Satisfaction Survey and make recommendations related to:

- The essential information to be obtained from completed Surveys;
- The specific questions to be asked in the Survey;
- The Protocol to be followed in the implementation of the Survey.

B. Discuss directions for further evaluation studied that emerged from the local evaluation.

Further Evaluation: Apply PPOR Analysis to Healthy Start Project Area.

In order to better target DHS efforts to improve racial disparity, additional analysis to better understand and define its underlying causes is required. CDC has identified a useful tool for defining and examining the underlying causes of preventable mortality and racial disparity called

the "Perinatal Periods of Risk Analysis" (PPOR). The PPOR Analysis has been recommended for implementation in Healthy Start Projects not only by CDC, but also by HRSA.

DHS is considering utilizing the Illinois Vital Records to complete a *Perinatal Periods of Risk (PPOR)* analysis that is relevant to not only the DHS Healthy Start Project, but all Healthy Start Projects in Illinois. More specifically, PPOR will be used to map the fetal/infant mortality by age, birth weight and race in order to assist the DHS Project in prioritizing prevention efforts; mobilizing communities and key actors; establishing ongoing surveillance; and enhancing FIMR findings/recommendations.

(Note: HBA has incorporated the PPOR Analysis into the Evaluation Plan for the Healthy Start Project and continues to participate in "Level II Training" sponsored by the Bureau of Maternal and Child Health related to implementation of the PPOR Analysis).

Section V. IMPACT BASED UPON THE RECOMMENDATIONS /RESULTS OF THE LOCAL EVALUATION

A. Describe changes in the perinatal system or any impact on the community in general that resulted from the local evaluation recommendations.

The DHS Healthy Start Project can document improvement in "Health Status" in the Project Area. Project Effectiveness can be measured by "changes in the health status and racial disparity indicators in the *Target Population*" and "changes in health status of the *Healthy Start Participants*."

Until vital records data for 2003 and 2004 is available, HBA will not be able to assist DHS in defining the full impact of the Healthy Start Project on the health status of participants and Target Area residents. However, the vital records data available suggests that the DHS Healthy Start Project is effective at improving health status of residents in the Project Area.

1. Changes in Health Status of *Target Area Population*

The infant mortality in the Healthy Start Project Area has decreased from 12.8 in 1997-99, to 11.5 in 2000-02. This represents a 10% improvement from the baseline data. It should be noted that all of this improvement in the infant mortality rate is attributable to improvements in the neonatal period. The neonatal mortality rate improved from 8.5 to 6.9 between 1997-99 and 2000-02 which is a 19% improvement. The available natality data suggests that VLBW in the Healthy Start Project Area has decreased from 2.5 in 1997-99, to 2.3 in 2000-02. This represents an 8% improvement from the baseline.

Changes in Health Status Indicators within Healthy Start Project Area

Indicator	1997-1999	2000-2002	Change

Infant Mortality	12.8	11.5	-10.0%
Neonatal Mortality	8.5	6.9	-19.0%
VLBW	2.5	2.3	-8.0%

B. Describe changes in project implementation, management or administration that resulted from the local evaluation results.

During the *Formative Phase* of the Local Evaluation, HBA and DHS worked with the participating Agencies to examine, design, and implement modifications to "implementation processes" that included:

- Outreach Activities;
- Risk Assessments;
- Use of Incentives;
- Staffing Patterns and Retention;
- Interface with Family Case Management;
- Cornerstone Data Collection Procedures; and
- Communication between/among Participating Agencies

During the *Process Phase* of the Evaluation, CQI activities led to conclusions, Focused Reviews, and ultimately changes in Project implementation and/or management and/or administration of the Project. These changes are highlighted below.

- All Agencies concluded that data entry on total number of prenatal medical visits was an issue to be addressed. All Agencies reviewed their data entry procedures and provided in service training that emphasized diligence in correct completion of the appropriate fields for all Healthy Start pregnant participants.

- All Agencies reviewed and refreshed their protocols and procedures related to **"reminding"** participants of their scheduled post partum visit and subsequently **"recalling"** participants who miss their appointments for post partum visit.

- All Agencies took aggressive action to assure that information captured on PA 10 related to "Adequacy of Prenatal Care" for pregnant participants was captured for all clients.

- Each Agency completed a review that determined the "primary reasons" that these Healthy Start participants miss a scheduled appointment with special emphasis on:

1. Pregnant Participants who miss a prenatal visit;
2. Child Participants who miss a Well-Child Visit and;
3. Pregnant Participants that miss their initial post partum visit.

- All Agencies agreed that it is necessary to revise and improve the Patient Satisfaction Survey for Healthy Start Clients. The Agencies, DHS Staff (i.e., nurses), and HBA have agreed to review the existing Patient Satisfaction Survey and make recommendations related to:

  - The essential information to be obtained from completed Surveys;
  - The specific questions to be asked in the Survey;
  - The Protocol to be followed in the implementation of the Survey.

  (Note: the task of revising the Patient Satisfaction Survey is scheduled to be completed in 2005).

- All Agencies concluded that data entry on EPSDT or Well-Child Exams in SV01 has been and may continue to be a problem. All agencies reviewed current data entry procedures and codes, and implemented in service training in order to emphasize diligence in correctly completing this screen for all Healthy Start children.

Section VI. PUBLICATIONS

Identify all publications resulting from the local evaluation(s) conducted. Give source, title and author(s). Place copy (ies) of any publication(s) in the appendices.

- HBA Annual Report (Executive Summary)
- HBA Annual Report

HEALTHY START LOCAL EVALUATION REPORT # 1

(Adequacy of Prenatal Care)

PROJECT NAME: **IDHS Healthy Start Project**

TITLE OF REPORT: **Agency Performance in Implementing Case Management (Adequacy of Prenatal Care)**

AUTHORS: **Hamilton•Bell Associates**

Section I: Introduction

The Evaluation Plan for the DHS Healthy Start Project calls for the establishment of a CQI Committee to routinely review data (Cornerstone) to monitor the Performance of all Grantees in the implementation of the five (5) required Core Services. Based on a review of all Performance Measures, the CQI Committee selected *% of Pregnant Participants with Adequate Prenatal Care* as an area for "Focused Review" by DHS, the Project Evaluator, and the Grantees.

A Local Evaluation or "Focused Review" was completed for this area in 2004.

Section II: Process

During the *Process Phase*, HBA played a leadership role in the design and institutionalization of a methodology for ongoing review and evaluation of key implementation processes. HBA designed and institutionalized a Continuous Quality Improvement Program (CQI). A CQI Committee was formed in order to provide the "structure" for review of data and make recommendations for modification of Agency activities.

The CQI Committee was comprised of the Project Director, representatives from participating Agencies, nursing staff responsible for oversight of case management agencies and data entry into Cornerstone, and the Local Evaluator (HBA).

The CQI Committee met every two or three months during 2005. At the end of the year, the Committee came together for the "Annual Meeting." Typically, there was a two part agenda for these CQI meetings. The first agenda item was to review and discuss HBA findings and recommendations based on the latest data in the quarterly Standard Reports. These Standard Reports were always provided to the Agencies prior to the CQI meetings. The second agenda item was to review "administrative issues" that may have surfaced since the last meeting. This may include updates on DHS policies on Agency reporting, billing, scheduling of Site-specific meetings, etc.

In general, the CQI meetings conclude with a consensus on the areas needing "improvement" and plans for conducting more "Focused Reviews" (a.k.a., Local Evaluation). The "Focused Reviews" that were approved by the CQI Committee were usually carried out by all four (4)

participating Agencies. However, on some occasions, the CQI Committee requested a specific Agency (that had been identified as an *"outlier"* on a specific performance measure) to conduct a Focused Review and report findings at the next CQI Meeting. These Reviews often led to changes in policies and/or implementation processes or procedures.

In summary, the CQI program has been effective in identifying and resolving barriers to Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., appropriate documentation of events and data entry into Cornerstone).

Section III: Findings/Discussion

1. Discussion

To Assure Improvement in Agency/System Performance, a CQI Structure and Process was put in place that included the following elements:

- Use of Valid and Reliable Data
- Capacity to Convert "Data to Information"
- Regular Review and Discussion among Key Actors
- Identification of Areas for Improvement
- Ability to Implement Change
- Monitoring Impact of Change

In the DHS Healthy Start Project, Continuous Quality Improvement (CQI) became an ongoing function where "strengths" were extrapolated and "weaknesses" addressed**.** During 2004, HBA and the CQI Committee identified *Adequacy of Prenatal Care* as an area for more focused review and improvement:

2. Findings:

The Focused Reviews resulted in the following findings related to "*Adequacy of Prenatal Care:"*

- The relevant data had to be captured in the PA10 Screen (Cornerstone)
- Data on PA10 can be completed by a number of staff from a variety of MCH Programs.
- Data is captured retrospectively after participant delivers and provides self-reported information on number of prenatal visits made.
- Data on PA10 can be "self-reported" and not documented
- Cornerstone does not use this field to develop a "tickler" file for Reminder/Recall activities (this is not a proactive use of data and Agencies were required to implement Reminder/Recall Systems according to contract).

3. Results:

- All Agencies concluded that the lack of data entry on the PA 10 screen related to "total number of prenatal medical visits" was an issue to be addressed. All agencies agreed to review current data entry procedures and emphasize diligence in completing this field for all Healthy Start pregnant participants.

- All Agencies concluded that they would review their current practice regarding **"reminding"** participants of their scheduled post partum visit and subsequently **"recalling"** participants who miss their appointments for post partum visit.

In summary, the Focused Reviews and CQI activity has been effective in identifying and resolving barriers to improving Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., data entry into Cornerstone). As a result of the efforts of the CQI Committee and the participating Agencies, the percentage of *Pregnant Participants with "Adequate Prenatal Care"* increased from 44.8% in 2003 to 55.4% in 2004.

Section IV: Recommendations

Policy, program, practice and other recommendations

- All Agencies should routinely monitor data entry for Cornerstone Screen PA10, related to "Adequacy of Prenatal Care" for Pregnant Participants.

- Each Agency should establish ongoing procedures to capture data on the "primary reasons" that these Healthy Start participants miss a scheduled appointment. Special emphasis should be placed on Pregnant Participants who miss a prenatal visit.

Section V: Impact

The Project Period Objective is to have 65% of the "high risk" Pregnant Participants receive "Adequate Prenatal Care" (Kessner Index) by 6/1/2005. A review of the data in Appendix 3 will find that the target level for this Project Period Objective has not been achieved. However, significant improvement was made between 2003 and 2004. In 2003, only 44.8% of the *Pregnant Participants* received "Adequate Prenatal Care." This performance measure became the focus of CQI activity during 2004. As a result of the efforts of the CQI Committee and the participating Agencies, the percentage of *Pregnant Participants* with "Adequate Prenatal Care" increased from 44.8% in 2003 to 55.5% in 2004.

A review of Agency-specific Performance finds that only one Agency (Erie Family Health Center) has achieved the target level (65%) for this Project Period Objective. Erie Family Health Center has documented that 70.6% of their *Pregnant Participants* had "Adequate Prenatal Care" in 2004. It should also be noted that two Agencies (Winfield Moody and West Side Future) had significant improvement in this performance measure between 2003 and 2004 (see Appendix 3). This performance measure will continue to be an area for CQI activity in 2005.

The ultimate impact that this documented improvement in "Adequacy of Prenatal Care" has on the health status of the high risk pregnant participant or newborn is difficult to assess. However, the Literature suggests that there is a link between health status of the pregnant woman and/or the newborn and "Adequate Prenatal Care." While final data for 2003 and 2004 is not available, data for 2001 and 2002 suggests there is improvement in health status (i.e., infant mortality) and determinants (i.e., birth weight) among Healthy Start participants.

Section VI: Publications

HBA Annual Report

HEALTHY START LOCAL EVALUATION REPORT # 2
(Well-Child Visits)

PROJECT NAME: **IDHS Healthy Start Project**

TITLE OF REPORT: **Agency Performance in Implementing Case Management (Well-Child Visits)**

AUTHORS: **Hamilton•Bell Associates**

Section I: Introduction

The Evaluation Plan for the DHS Healthy Start Project calls for the establishment of a CQI Committee to routinely review data (Cornerstone) to monitor the Performance of all Grantees in the implementation of the five (5) required Core Services. Based on a review of all Performance Measures, the CQI Committee selected *% of Child Participants Current with Well-Child Exams* as an area for "Focused Review" by DHS, the Project Evaluator, and the Grantees.

A Local Evaluation or "Focused Review" was completed for this area in 2004.

Section II: Process

During the *Process Phase*, HBA played a leadership role in the design and institutionalization of a methodology for ongoing review and evaluation of key implementation processes. HBA designed and institutionalized a Continuous Quality Improvement Program (CQI). A CQI Committee was formed in order to provide the "structure" for review of data and make recommendations for modification of Agency activities.

The CQI Committee was comprised of the Project Director, representatives from participating Agencies, nursing staff responsible for oversight of case management agencies and data entry into Cornerstone, and the Local Evaluator (HBA).

The CQI Committee met every two or three months during 2005. At the end of the year, the Committee came together for the "Annual Meeting." Typically, there was a two part agenda for these CQI meetings. The first agenda item was to review and discuss HBA findings and recommendations based on the latest data in the quarterly Standard Reports. These Standard Reports were always provided to the Agencies prior to the CQI meetings. The second agenda item was to review "administrative issues" that may have surfaced since the last meeting. This may include updates on DHS policies on Agency reporting, billing, scheduling of Site-specific meetings, etc.

In general, the CQI meetings conclude with a consensus on the areas needing "improvement" and plans for conducting more "Focused Reviews" (a.k.a., Local Evaluation). The "Focused Reviews" that were approved by the CQI Committee were usually carried out by all four (4)

participating Agencies. However, on some occasions, the CQI Committee requested a specific Agency (that had been identified as an *"outlier"* on a specific performance measure) to conduct a Focused Review and report findings at the next CQI Meeting. These Reviews often led to changes in policies and/or implementation processes or procedures.

In summary, the CQI program has been effective in identifying and resolving barriers to Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., appropriate documentation of events and data entry into Cornerstone).

Section III: Findings/Discussion

1. Discussion

   To Assure Improvement in Agency/System Performance, a CQI Structure and Process was put in place that included the following elements:

   - Use of Valid and Reliable Data
   - Capacity to Convert "Data to Information"
   - Regular Review and Discussion among Key Actors
   - Identification of Areas for Improvement
   - Ability to Implement Change
   - Monitoring Impact of Change

   In the DHS Healthy Start Project, Continuous Quality Improvement (CQI) became an ongoing function where "strengths" were extrapolated and "weaknesses" addressed**.** During 2004, HBA and the CQI Committee identified *Well-Child Visits* as an area for more focused review and improvement:

2. Findings:

   The Focused Reviews resulted in the following findings related to *"Well Child Visits:"*

   - Data captured on SV01 Screen
   - Data on SV01 cannot be "self-reported" and must be documented
   - Cornerstone does not use this field to develop a "tickler" file for Reminder/Recall activities
   - This is not a proactive use of data and Agencies are required to implement Reminder/Recall Systems according to contract.
   - All Agencies indicated that there has been a history of problems with using the correct codes to reflect the receipt of an EPSDT or Well-Child Exam on the SV01 Screen. The correct code for Type of Service for an EPSDT exam is "806."
   - Agencies were not clear on the definition of an EPSDT Exam and often equated this with the receipt of immunizations.
   - The Agencies generally expressed "frustration" with obtaining documentation from providers other than their own Health Center.

3. Results:

- All Agencies concluded that data entry on EPSDT or Well-Child Exams in SV01 has been and may continue to be a problem. All agencies agreed to review current data entry procedures, and codes and to emphasize diligence in completing this field for all Healthy Start active children in the first six (6) months of 2004 (*target date for completion is August 1, 2004)*.

- All Agencies concluded that they would review their current practice regarding **"reminding"** participants of their scheduled Well-Child Exam and subsequently **"recalling"** participants who miss their appointments for the Well-Child Exam.

In summary, the Focused Reviews and CQI activity has been effective in identifying and resolving barriers to improving Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., data entry into Cornerstone). As a result of the efforts of the CQI Committee and the participating Agencies, the percentage of *Child Participants Current with "Well Child Exams"* increased from 42.2% in 2003 to 60.8% in 2004.

Section IV: Recommendations

Policy, program, practice and other recommendations

- Each Agency should establish ongoing procedures to capture data on the "primary reasons" that these Healthy Start participants miss a scheduled appointment. Special emphasis should be placed on Child Participants who miss a Well-Child Visit.

- Take aggressive action to assure that information captured on SV01 related to EPDST or Well-Child Visits will be captured for all Child Participants.

Section V: Impact

The Project Period Objective is to have 65% of participating children (age 0-2) current with Well-Child Exams by 6/1/2005. A review of the data in Appendix 3, will find that the target level for this Project Period Objective has not been achieved. However, significant improvement was made between 2003 and 2004. In 2003, only 42.2% of the participating children were current with their Well-Child Exams. HBA identified this performance measure as needing significant improvement in 2004. This performance measure became the focus of CQI activity during 2004. As a result of the efforts of the CQI Committee and the participating Agencies, the percentage of children that were current with Well-Child Exams increased from 42.2% in 2003 to 60.8% in 2004.

Given the improvement that DHS has made in the interface between IDPA Paid Claims and Cornerstone, HBA anticipates that the Healthy Start Project is well positioned to reach the target level (65%) for this Project Period Objective. This performance measure will continue to be targeted for CQI activity in 2005.

The ultimate impact that this documented improvement in "Well Child Visits" has on the health status of participating children is difficult to assess. However, the Literature suggests that there is a link between compliance with Well Child Exam (i.e., EPSDT requirements that include immunizations, age appropriate screenings, and education) and the health status of children.

Section VI: Publications

HBA Annual Report

HEALTHY START LOCAL EVALUATION REPORT # 3

(Interconceptional Participants Completing Initial Post Partum Visit)

PROJECT NAME: **IDHS Healthy Start Project**

TITLE OF REPORT: **Agency Performance in Implementing Case Management (Participants Completing Initial Post Partum Visit)**

AUTHORS: **Hamilton•Bell Associates**

Section I: Introduction

The Evaluation Plan for the DHS Healthy Start Project calls for the establishment of a CQI Committee to routinely review data (Cornerstone) to monitor the Performance of all Grantees in the implementation of the five (5) required Core Services. Based on a review of all Performance Measures, the CQI Committee selected *% of Interconceptional Participants Completing Initial Post Partum Visit* as an area for "Focused Review" by DHS, the Project Evaluator, and the Grantees.

A Local Evaluation or "Focused Review" was completed for this area in 2004.

Section II: Process

During the *Process Phase*, HBA played a leadership role in the design and institutionalization of a methodology for ongoing review and evaluation of key implementation processes. HBA designed and institutionalized a Continuous Quality Improvement Program (CQI). A CQI Committee was formed in order to provide the "structure" for review of data and make recommendations for modification of Agency activities.

The CQI Committee was comprised of the Project Director, representatives from participating Agencies, nursing staff responsible for oversight of case management agencies and data entry into Cornerstone, and the Local Evaluator (HBA).

The CQI Committee met every two or three months during 2005. At the end of the year, the Committee came together for the "Annual Meeting." Typically, there was a two part agenda for these CQI meetings. The first agenda item was to review and discuss HBA findings and recommendations based on the latest data in the quarterly Standard Reports. These Standard Reports were always provided to the Agencies prior to the CQI meetings. The second agenda item was to review "administrative issues" that may have surfaced since the last meeting. This may include updates on DHS policies on Agency reporting, billing, scheduling of Site-specific meetings, etc.

In general, the CQI meetings conclude with a consensus on the areas needing "improvement" and plans for conducting more "Focused Reviews" (a.k.a., Local Evaluation). The "Focused Reviews" that were approved by the CQI Committee were usually carried out by all four (4) participating Agencies. However, on some occasions, the CQI Committee requested a specific Agency (that had been identified as an *"outlier"* on a specific performance measure) to conduct a Focused Review and report findings at the next CQI Meeting. These Reviews often led to changes in policies and/or implementation processes or procedures.

In summary, the CQI program has been effective in identifying and resolving barriers to Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., appropriate documentation of events and data entry into Cornerstone).

Section III: Findings/Discussion

1. Discussion

   To Assure Improvement in Agency/System Performance, a CQI Structure and Process was put in place that included the following elements:

   - Use of Valid and Reliable Data
   - Capacity to Convert "Data to Information"
   - Regular Review and Discussion among Key Actors
   - Identification of Areas for Improvement
   - Ability to Implement Change
   - Monitoring Impact of Change

   In the DHS Healthy Start Project, Continuous Quality Improvement (CQI) became an ongoing function where "strengths" were extrapolated and "weaknesses" addressed**.** During 2004, HBA and the CQI Committee identified *% of Interconceptional Participants Completing Initial Post Partum Visit* as an area for more focused review and improvement:

2. Findings:

   The Focused Reviews resulted in the following findings related to "*% of Interconceptional Participants Completing Initial Post Partum Visit:"*

   - Relevant data could be captured on either PA10 or SV01 Cornerstone Screens.
   - There was no clear direction or procedure that instructed the participating Agencies on which Cornerstone screen should be used to document where a post partum visit should be captured and whether or not this visit must be documented.
   - Data on PA10 can be "self-reported" and does not need to be documented while data on SV01 Screen cannot be self-reported and must be documented.

- Documentation on visit date on PA10 is often used by WIC and once used, cannot be used to capture date of post partum visit.
- Agencies suggested that SV01 screen may be more appropriate place for capturing initial post partum visit, and the code of "820" should be used to capture the initial post partum visit.
- Cornerstone does not use this field to develop a "tickler" file for Reminder/Recall activities (this is not a proactive use of data and Agencies are required to implement Reminder/Recall Systems according to contract).
- All Agencies indicated that there has been a history of problems with using the correct codes to reflect the receipt of services on the SV01 Screen.
- Some Agencies did not sufficiently comprehend the DHS and Federal Guidance which requires Agencies to follow participants for up to two (2) years after delivery (Interconceptional Care).

3. Results:

- All Agencies concluded that capturing the date of the initial post partum visit appears to be a "Cornerstone System Issue." It is clear that the use of the PA 10 Screen to capture the post partum visit date is compromised by this field being completed by WIC staff prior to the post partum exam.

- All Agencies agreed to immediately utilize only the SV01 screen to capture information on the Initial Post Partum Visit. DHS subsequently developed a procedure that provided correct guidance for capturing information relative to Initial Post Partum Visits.

- All Agencies concluded that they would review their current practice regarding **"reminding"** participants of their scheduled post partum visit and subsequently **"recalling"** participants who miss their appointments for their post partum visit.

In summary, the Focused Reviews and CQI activity has been effective in identifying and resolving barriers to improving Agency performance in implementing the Core Services and meeting other DHS expectations (i.e., data entry into Cornerstone). As a result of the efforts of the CQI Committee and the participating Agencies, the percentage of *Interconceptional Participants Completing the Initial Post Partum Visit"* increased marginally from 30.5% in 2003 to 32.2% in 2004. However, it should be noted that corrective action was not taken until the last two months of 2004. It is anticipated that there will be significant improvement during 2005.

Section IV: Recommendations

Policy, program, practice and other recommendations

- All Agencies should establish procedures to routinely monitor data entry for Cornerstone Screen SV 01 related to Initial Post Partum Visits.

- Each Agency should establish ongoing procedures to capture data on the "primary reasons" that these Healthy Start participants miss a scheduled appointment for an Initial Post Partum Exam.

Section V: Impact

While DHS did not formally establish a Project Period Objective for *Completion of the Initial Post Partum Visit* by *Pregnant Participants* who delivered, the Evaluation Plan calls for monitoring this critical event. The initial post partum visit represents the point of transition between a *"Pregnant Participant"* and an *"Interconceptional Participant."* A review of the data in Appendix 3 finds that for 2003 and 2004, approximately 31% of the *Pregnant Participants* are documented in Cornerstone as having completed their initial post partum visit.

The data in Appendix 3 documents that the range in the percentage of *Pregnant Participants* who complete the initial post partum visit varies from a low of 20.0% (Erie Family Health Center) to a high of 50.5% (Henry Booth House). Preliminary discussions by the CQI Committee have focused attention on the completeness and reliability of the Cornerstone data for this performance measure. It is anticipated that the CQI Committee will select this performance measure as an area for "Focused Review" by all participating Agencies in 2005.

The ultimate impact that improvement in the percentage of pregnant participants who *"Complete their Initial Post Partum Visit"* has on the health status of Interconceptional Women is difficult to assess. However, these women are hard to reach, high-risk pregnant women when initially enrolled in the DHS Healthy Start Project, and they must return for their Post Partum Visit to receive the benefit of the Interconceptional Care component of this Project. Those pregnant participants who do not return for a Post Partum Visit and are "lost to follow up" are likely to remain high risk for a poor outcome of pregnancy. The DHS Healthy Start Project has targeted this area for further improvement in 2005.

Section VI: Publications

HBA Annual Report

APPENDICES

Appendix 1

Risk Profile of Healthy Start Pregnant Participants
Provisional Data: 2003-2004

Project		Erie		Henry Booth		Westside Future		Winfield Moody	
High Risk Criteria	**%**	**Rank**	**%**	**Rank**	**%**	**Rank**	**%**	**Rank**	**%**
Low Educational Attainment	19.3%	2	24.0%	4	11.5%	2	18.0%	1	22.1%
Homeless/Temporary Housing	18.8%	1	27.4%	3	11.5%*	3	15.7%*	2	17.9%
Diseases that Effect Pregnancy	16.7%	3	12.5%	2	21.2%*	1	21.7%	3	11.8%
> 4th Pregnancy or 3rd Child Expected	12.1%	4	10.2%	1	22.4%	4	11.6%	6	7.0%
Previous Preterm Birth	6.6%	6	5.9%	5	8.4%	6	7.1%	7	5.5%
Alcohol or Other Substance Abuse	6.0%	9	2.3%	8	3.4%	5	10.2%	5	7.8%

Appendix 2

Comparison of "Selected" Performance Measures: 2003 vs. 2004

Outreach

ures	Total		Winfield Moody		Erie Family Health Center		Henry Booth House		West Side Future	
	2003	2004	2003	2004	2003	2004	2003	2004	2003	2004
en Enrolled**	665	673	143	117	195	181	132	158	195	217
enatal Care mester**	82.9%	82.6%	69.5%	69.0%	90.6%	90.6%	85.7%	77.6%	84.2%	84.2%
Women Enrolled	798	860*	215[1]	205[1]	190	210*	180	202*	213	243*
2 Enrolled	792	837*	253[1]	247[1]	171	193*	181	192	187	205*

licates Improvement in Number of Participants Enrolled between 2003 and 2004.
licates that DHS has submitted a Project Period Objective to HRSA for this Measure.
QI Issue for Agency Specific Focused Review

Appendix 3

Comparison of "Selected" Performance Measures: 2003 vs. 2004

Case Management (Page 1 of 2)

ures	Total		Winfield Moody		Erie Family Health Center		Henry Booth House		West Side Future	
	2003	2004	2003	2004	2003	2004	2003	2004	2003	2004
nts										
renatal Care**	44.8%	55.5%*	29.5%	35.2%*	68.6%	70.6%	51.6%	52.3%	44.6%	50.7%*
C**	77.4%	83.4%*	71.3%	79.5%*	75.4%	84.5%*	79.5%	81.0%	82.6%	86.2%
ell-Child Exams**	42.2%	60.8%*	31.1%	53.8%*	69.0%	82.9%*	41.4%	58.3%*	33.2%	50.7%*
munizations**	72.0%	70.8%	54.9%	57.5%	84.8%	79.8%	79.0%	78.1%	76.5%[1]	71.7%[1]
Participants Partum Visit	30.5%	32.2%	21.0%	23.9%	29.7%[1]	20.0%[1]	30.8%	50.5%*	38.1%[1]	30.5%[1]

licates improvement of five (5) or more percentage points in this performance measure.
licates that DHS has submitted a Project Period Objective to HRSA for this measure.
)I Issue for Agency Specific Focused Review

Appendix 4

Comparison of "Selected" Performance Measures: 2003 vs. 2004

Case Management-Medical Home (Page 2 of 2)

ures	Total		Winfield Moody		Erie Family Health Center		Henry Booth House		West Side Future	
	2003	2004	2003	2004	2003	2004	2003	2004	2003	2004
*rticipants***	99.4%	98.5%	99.3%	97.4%	100.0%	100.0%	100.0%	98.1%	98.5%	98.2%
ipants (0-2)	42.2%	60.8%*	31.2%	53.8%*	69.0%	82.9%*	41.4%	58.3%*	33.2%	50.7%*
*l Participants***	98.6%	99.1%	97.2%	98.5%	100.0%	100.0%	100.0%	99.0%	97.7%	98.8%

licates improvement of five (5) or more percentage points in this performance measure.
licates that DHS has submitted a Project Period Objective to HRSA for this measure.

Appendix 5

Comparison of "Selected" Performance Measures: 2003 vs. 2004

Health Education

ures	Total		Winfield Moody		Erie Family Health Center		Henry Booth House		West Side Future	
	2003	2004	2003	2004	2003	2004	2003	2004	2003	2004
ant Women who se in Drinking hol[2]	77.4%	80.0%	90.0%	66.7%	75.0%	100.0%	83.3%	83.3%	63.6%	82.4%
ant Women who e in Smoking**	63.9%	63.4%	64.1%	54.1%	75.0%	72.7%	54.3%	50.0%	66.7%	70.2%
nceptional Women Use of Family ing**	73.4%	70.5%	60.0%	45.1%	93.0%	79.4%	73.6%	69.2%	65.5%	74.0%*

dicates improvement in this performance measure between 2003 and 2004.
nall numbers involved in calculation of percents (Range = 3 to 17).

Section VII: Fetal and Infant Mortality Review (FIMR)

The Fetal and Infant Mortality Review (FIMR) process, developed by the American College of Obstetricians and Gynecologists, examines community-based service delivery problems and non-medical factors that may contribute to a fetal or infant death. Illinois' FIMR project follows the general protocol developed by the American College of Obstetrics and Gynecology for the National FIMR project. Through the CHSI, the Department has successfully implemented a Fetal and Infant Mortality Review (FIMR) process, established in July 2001 that included fetal and neonatal deaths in the entire city of Chicago. Cases are identified through the state's birth defects surveillance system and by reporting of fetal deaths to the CDPH. Two nurses from the University of Chicago perinatal center, as agents of CDPH, complete home interviews and abstract medical records. Participation is voluntary, and no records are abstracted if women refuse to participate. A multidisciplinary team reviews each case and assigns one of two dispositions ("unavoidable" or "potentially avoidable") to each case. The team has completed 65 case reviews during the last two years. Nine of 28 fetal deaths and 14 of 37 neonatal deaths were classified as "potentially avoidable." The team made 126 recommendations through these reviews. The recommendations address provider and patient education, especially with regard to the identification and treatment of premature labor.

Section VIII: Products

The Department is enclosing a copy of the Fetal Infant Mortality Review (FIMR) Report as required. It may be found under Attachment 2.

nt 1: Symptoms of Postpartum (Perinatal) Mood Disturbances

	Baby Blues Transitory, minor affective disorder. Used most commonly to describe the weeping and emotional instability that occurs during the first postpartum week. **Estimated Incidence per number of births: 60 to 80 out of 100**	Postpartum Depression More debilitating than the "Blues" and more common than postpartum psychosis. Characterized by despondency, tearfulness, feelings of inadequacy, guilt, irritability and fatigue. **Estimated incidence per number of births: 8 to 10 out of 100**	Postpartum Psychosis A relatively rare disorder following childbirth similar to general psychotic reactions: confusion, agitation, delusions or auditory hallucinations. **Estimated incidence per number of births: 1 to 2 out of 1000**
mptoms	Lack of sleep No energy Food cravings Loss of appetite Feeling tired even after sleeping	Headaches Numbness, tingling in limbs Chest pains Heart palpitations Hyperventilation	Refusal to eat Inability to stop activity Frantic excessive energy Hyperactivity Rapid speech
l States	Anxiety Excessive worry Confusion Overly concerned over physical changes Nervousness Feeling "I am not myself" or "This isn't me" Lack of confidence Sadness Feeling overwhelmed	Despondency Despair Feelings of inadequacy Inability to cope Hopelessness Overly concerned for baby's health Impaired concentration and/or memory Loss of normal interests Suicidal thoughts Bizarre or strange thoughts	Extreme confusion Loss of memory Incoherent Bizarre hallucinations Hearing voices Delusions

l Reactions	Increased crying Hyperactivity Excitability Over sensitivity Feelings hurt easily Irritability Lack of feeling for the baby Poor sleeping Mood changes A sense of vulnerability	Extreme behavior Panic attacks Hostility New fears or phobias Hallucinations Nightmares Extreme guilt No feelings for the baby Overly concerned for the baby Feeling out of control Feeling like “you are going crazy”	Suspiciousness Irrational statements Preoccupation with trivia Mania Rapid speech

Fetal & Infant Mortality Review Project

City of Chicago, Illinois

Submitted by
FIMR Project

Staff

September 2004

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Overall Reduction in Infant Deaths

Over the past several years, there has been an overall reduction in the rate at which infants do not survive until their first birthday. Within the City of Chicago, in 1993 approximately 14 in every 1,000 infants born died. By 1997 that number was decreased to 11 in every 1,000 infants that did not survive until their first birthday. Infant mortality rates in Chicago fell from 9.0 in 2001 to 8.6 in 2002, the lowest rate ever recorded by the city. The increase in infant mortality for 1999 was largely attributed to the increased rates for short gestation/low birth weight*. This is represented in neonatal mortality rates, which are defined as deaths that occur within the first 28 days of life per 1000 live births.

There are several indicators that can predict the health of Chicago's residents and evaluate maternal-child health outcomes. Prematurity (Short Gestation) is defined as infants born alive before 37 completed weeks of gestation, (full term is 40 weeks). Prematurity is the number one contributor to infant mortality. Low Birth Weight infants, born 5.5 pounds or less, also contributes to infant mortality rates, especially those with very low birth weights.

Racial Disparities Persist

Unfortunately, not all racial/ethnic groups have benefited from the reduction in deaths equally. Despite the declining pattern of Black and White Infant Mortality Rates (IMR), a substantial gap between Black and White for Chicago residents continues to exist although it has narrowed over the years. Mortality rates for the overall Chicago Hispanic and Non-Hispanic White communities have increased slightly over the years.

Percent of Low Birth Weight*

All Births - **1993**	11.2	All Births - **1999**	10.1
Non-Hispanic White	6.8	Non-Hispanic White	6.5
Non-Hispanic Black	16.4	Non-Hispanic Black	15.1
Total Hispanic	6.6	Total Hispanic	6.8

All Births - **2000**	10.5	All Births - **2001**	9.0
Non-Hispanic White	5.4	Non- Hispanic White	6.0
Non-Hispanic Black	11.3	Non-Hispanic Black	11.7
Total Hispanic	5.2	Total Hispanic	5.9
All Births - **2002**	8.6		
Non-Hispanic White	6.5		
Non-Hispanic Black	11.4		
Total Hispanic	5.3		

Percent of Births with Short Gestations *

All Births 1998	14.8	All Births 2000	
Non-Hispanic White	10.4	Non-Hispanic White	10.3
Non-Hispanic Black	19.6	Non-Hispanic Black	19.4
Total Hispanic	12.3	Total Hispanic	11.7
All Births **2001**		All Births **2002**	
Non-Hispanic White	10.9	Non-Hispanic White	11.4
Non-Hispanic Black	19.4	Non-Hispanic Black	19.5
Total Hispanic	12.3	Total Hispanic	12.3

*Infant Mortality Rates**

All Races – **1993**	13.7	All Races – **1999**	11.5
Non-Hispanic White	7.8	Non-Hispanic White	7.5
Non-Hispanic Blacks	20.4	Non-Hispanic Black	17.5
Total Hispanic	7.2	Total Hispanic	7.9
All Races - **2000**	10.5	All Races - **2001**	9.0
Non-Hispanic White	5.7	Non- Hispanic White	6.2
Non-Hispanic Black	15.8	Non-Hispanic Black	14.9
Total Hispanic	8.1	Total Hispanic	5.3

Total Births – **2002**	8.6
Non-Hispanic White	5.1
Non-Hispanic Black	14.8
Total Hispanic	

Neonatal Mortality Rates*

All Races - **1993**	8.5	All Races – **1999**	7.7
Non-Hispanic White	5.4	Non-Hispanic White	5.3
Non-Hispanic Black	12.4	Non-Hispanic Black	11.2
Total Hispanic	4.4	Total Hispanic	5.7
All Races - **2000**		All Races - **2001**	
Non-Hispanic White	4.6	Non-Hispanic White	5.3
Non-Hispanic Black	9.7	Non-Hispanic Black	8.8
Total Hispanic	5.4	Total Hispanic	3.5

Fetal Mortality Rates**

All Races-**2000**	9.4	All Races - **2001**	8.**7**
Non-Hispanic White	7.1	Non-Hispanic White	6.3
Non-Hispanic Black	13.3	Non-Hispanic Black	12.5
Total Hispanic	5.8	Total Hispanic	5.1

All Races - **2002**	**7**.4
Non-Hispanic White	6.3
Non- Hispanic Black	9.7
Total Hispanic	5.5

* (City of Chicago, Department of Public Health, Epidemiology Program Reports, March 2002 and March 2004)

** (IDPH/CHS/Schmidt, April 26, 2004)

Overview of the Fetal & Infant Mortality Review Program (FIMR)

FIMR, a nationwide program supported by the American College of Obstetricians and Gynecologists (ACOG), Healthy Start and the Department of Human Services, is designed to identify the non-medical factors that contribute to adverse pregnancy outcomes. Once identified, FIMR empowers the community and its leadership to develop and implement solutions and systems to breakdown the barriers to optimize perinatal outcomes.

Illinois' FIMR Program is a voluntary program supported by a federal grant in collaboration with the Illinois Department of Human Services and the Chicago Department of Public Health. It identifies fetal deaths, (infants born dead after the 20th week of gestation) and neonatal deaths, (any live born infant regardless of gestational age and weight), who dies within the first 28 days of life. These parameters were chosen for the following reasons:

- There is an Illinois state mandated process in place within the hospitals to review these cases from a medical perspective
- The social and economic factors are rarely available during the state mandated medical reviews
- As per the statistics above, early losses, whether fetal or neonatal deaths, are prevalent within the City of Chicago

The program consists of case identification (residents within the 606 zipcode are eligible to participate), outreach to enroll women/family's into the program through an informed consent process, an in-home interview, medical record abstraction, and case reviews by a multidisciplinary team.
Case identification consists of:

- Neonatal deaths reported to The Adverse Pregnancy Outcome Reporting System (APORS), a statewide reporting system to identify infants born with birth defects, neonatal deaths and infants requiring specialized nursing follow-up – 933 cases referred
- Fetal death (stillborns) referrals through a reporting form generated by the individual hospital and sent directly to the FIMR office – 345 cases referred

The case review process includes:

- Summarization of in-home interview and medical record abstract
- Case presentation with input from interviewer
- Discussion by the team as to factors that impacted pregnancy

- Dispositions, either unavoidable (everything was done to promote a positive outcome) or potentially avoidable (issue arose, either for the patient or health care system that if changed, may have had a different outcome), are assigned to each case reviewed by committee consensus.

- Factors and recommendations, both general and individual, are also defined for each case reviewed.

This report represents a summary of the individual case findings, documented dispositions, along with a summary of the factors and recommendations identified through the review process. See Appendix C for ZIP Code specific participants.

Findings and Recommendations

The chart below represents all of the cases reviewed by the Case Review Team, categorized by type of death and disposition.

Summary of Total Cases Reviewed by FIMR Case Review Team

	Total		Fetal deaths	Neonatal deaths
Potentially Avoidable	23		9	14
Unavoidable	42		19	23
	65		28	37

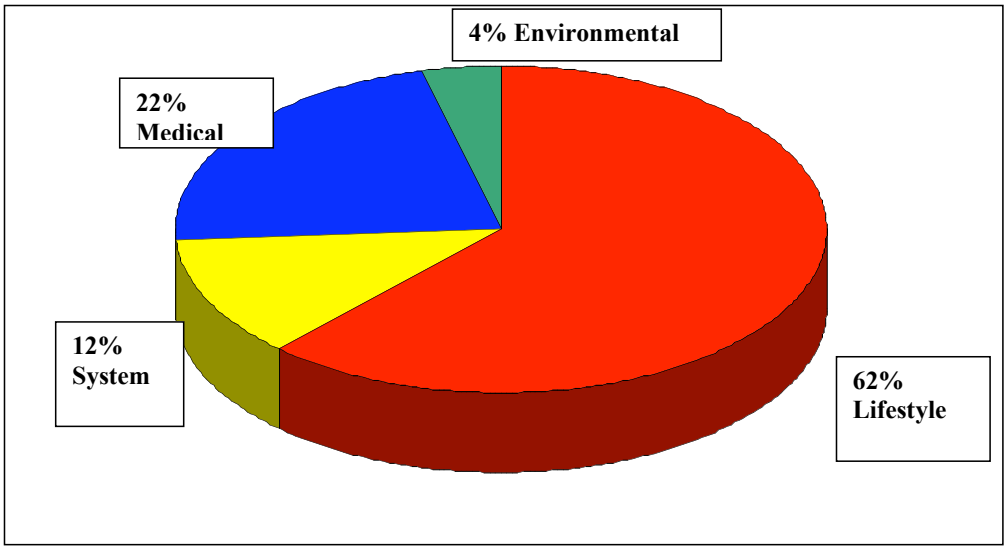
Categories of Cases

After several Case Review Team meetings and at the completion of approximately thirty reviews, the team met to identify categories of like factors that possibly contributed to the adverse outcomes. These like factors were collapsed into four general categories and apply to all of the 65 cases. The following are the categories identified by the review team:

- Lifestyle Issues – individual behaviors that impacted the pregnancy
- Systems Issues – communication breakdowns between agencies and providers, lack of appropriate referrals or knowledge of available resources, and education issues related to providers, clients and the community
- Medical Issues – management of pre-existing medical conditions and issues related to current pregnancy or post partum period
- Environmental Issues – issues related to the individual's immediate environment, including family and social support systems and physical environment including chemical and toxin exposures.

(See chart for category breakdown)

Categories of Cases



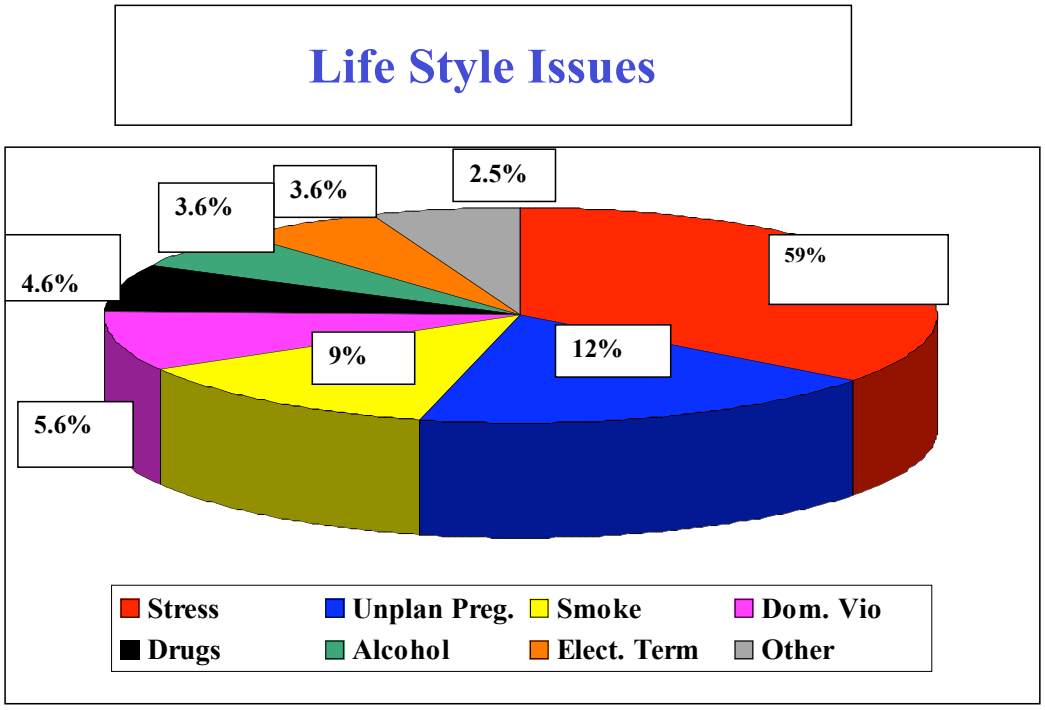
The category of Life Style Issues contains factors related to individual behaviors that impact pregnancy. These factors were identified by clients and or interviewer during the in-home visit and were evaluated by the review team as to their impact on the pregnancy outcome.

Below is a list of the factors identified within this category:

- Self Reported Stress During Pregnancy
- Unplanned pregnancy
- Smoke/smoke exposure
- Alcohol/drug usage
- Domestic Violence
- Teen Pregnancy
- No consumption of Folic Acid prior to pregnancy
- Short pregnancy intervals
- Became pregnant while taking contraceptives
- Homelessness
- No prenatal care or late prenatal care

- Utilizes ER for primary health care
- Lack of follow through with post partum check-up
- Late presentation for care at delivery
- Multiple elective pregnancy terminations

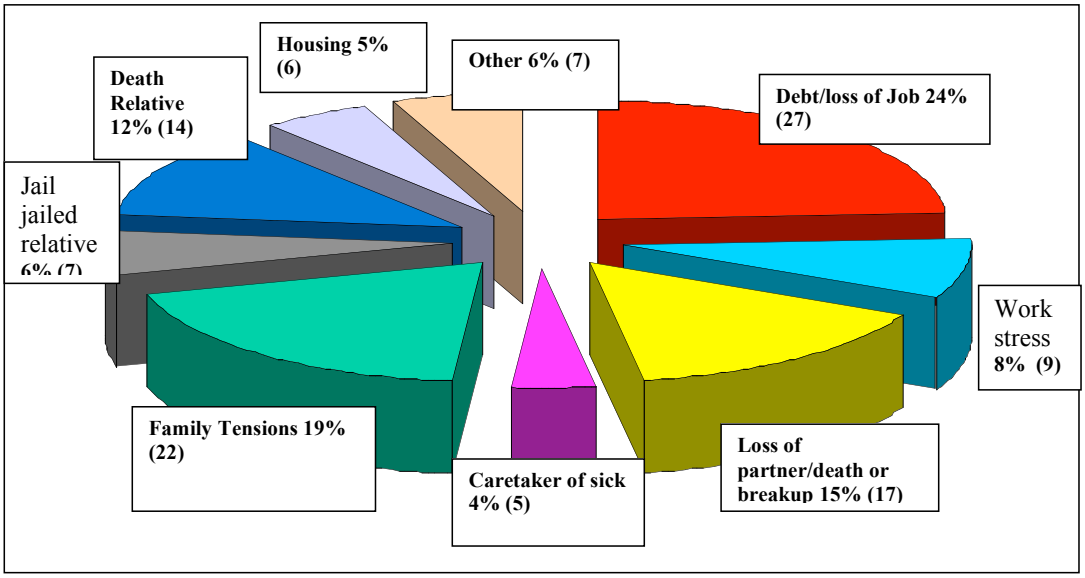
See chart below for breakdown



Life Style Issues and related factors were cited more often that any other category. As a sub-section of the larger category, Self Reported Stress had the highest percentage rate. This category identifies stressors perceived by the client during her pregnancy and discussed during the interview.

To further analyze the sub-category of "Self Reported Stress", the chart below represents the breakdown of factors within this sub-category.

Stress During Pregnancy



Systems Issues

The second category is systems issues, which relate to:

- Communication breakdowns between agencies and providers
- Lack of coordination between Medicaid and SSI
- Lack of appropriate referrals or knowledge of available resources
- Education issues related to providers, clients and the community
- Lack of WIC and/or Case Management
- Lack of consistency when seeing multiple providers for Prenatal Care
- Insurance issues – change in carrier or loss of insurance
- Lack of case management intervention
- Lack of school intervention

Medical Issues

The third category, Medical Issues, relates to management of pre-existing medical conditions and issues related to current pregnancy or post partum period. Below are the factors within this category:

- Congenital anomaly
- Depression
- Family Planning issues
- Lack of risk assessment
- Infections
- Incompetent cervix
- Previous pre-term labor
- Pre-term labor
- Maternal pre-existing conditions
- Medical conditions related to current pregnancy
- Multiple birth pregnancy
- Lack of pregnancy evaluation during sick physician visits

Environmental Issues

The last category, Environmental Issues, relates to:

- Housing issues and perceived unsafe environment
- Lack of family and social support systems
- Physical environment including chemical and toxin exposures
- Social violence

Recommendations

The review of 65 cases by the multidisciplinary Case Review Team listed 126 recommendations over the past two-year period. Each case reviewed generated specific recommendations. In cases with similar factors recurring, there was repetition of the same recommendations. The recommendations listed in this report are the result of collapsing and combining the original 126 recommendations. Emerging from these, the recommendations were placed in the following categories:

Community/Agency/Systems Recommendations

- Provide referral for obstetrical evaluation and services for homeless women
- When women are arrested or incarcerated, provide health/pregnancy evaluations
- Evaluate provision of services in health care settings, especially in areas of communication and consistency
- Recommend more frequent case management contacts with patients during pregnancy, especially those identified as high risk
- Provide reproductive education in schools
- Recommend schools identify pregnancy early and make appropriate referrals
- Educate Emergency Room staff on need for comprehensive obstetrical assessments
- Increase local agency outreach for:
    - Case finding and refer to appropriate social or medical agency
    - Educate community on expanded medical coverage for women during pregnancy
    - Heighten community awareness of housing, safety and environmental issues

Education Recommendations

Provide educational programs for providers for the following areas:

- Domestic violence assessment multiple times during pregnancy
- Depression assessment

- More effective family planning instructions with assessment of client understanding
- Kick Count education with assessment of patient understanding
- Risk assessment/general health evaluation with referral to higher level of care
- Understanding of cultural differences
- Providing information at a level that the client can understand and evaluate client understanding
- Need for non-judgmental assessment and provision of services for clients with risk behaviors
- Evaluation of pregnancy status during routine or sick visits
- Resources available for social and community services and how to access the services

Provide educational programs for client's concerning:

- Identification of sign and systems of problems during pregnancy
- Sexually transmitted diseases and HIV
- Importance of kick counts and assessment of fetal movement to avoid fetal deaths
- Importance of Well Baby Care
- Reproductive health issues for all ages
- Nutritional issues and weight management
- Need for routine general health follow-up
- Need for grief counseling and social support systems
- Importance of providing good reproductive history to medical providers for current and future pregnancies
- Necessity of early, consistent prenatal care and post partum follow-up
- Stress management skills before, during and after pregnancy
- Adverse effects of drugs/alcohol and tobacco on overall health

Funding and Policy Recommendations:

- Develop linkage between Medicaid and SSI coverage to trigger case management/WIC referral
- Increased community resources for:
  Preconceptual counseling

Family planning resources
Genetic counseling
Smoking cessation programs specific for pregnant women
Counseling for drug/alcohol usage
Counseling for mental health issues and depression
Community programs for job training
Parenting classes
Home health and hospice services within the community
Domestic Violence
Provide services for anger management and aggressive behaviors issues
Bereavement counseling and support

Conclusion:

The strength of the FIMR Program is its ability to look at individual cases with a holistic view and make recommendations that transcends various disciplines, organizations, systems and specialties. A unique feature of the Illinois FIMR Program is the in-home interview, which allows the client to share her individual perspective of her adverse pregnancy with the interviewer. She also has the opportunity to accept referrals, when the need is identified. This approach gives the Case Review Team members both the client's and medical providers perspective on the events that lead to the adverse outcome.

This report is the summary of the factors and recommendations of the Case Review Team. It is their expectation that this will be reviewed by community, local, and state leadership and innovative, comprehensive community based programs will be developed to improve overall perinatal outcomes.

Appendix A

Case review Team Members

Margaret Davis	Director – Office Community Health Health Care Consortium of Illinois
Sharon Harold	Hospital Advocacy Program Coordinator South Suburban Family Shelter
Rebecca Holbrook	Director of Community Education Planned Parenthood
Susana Lopatka, R.N. Consultatnt	Retired - MCH Public Health nurse
Agatha Lowe, Ph. D. Programs	Director of Women & Childrens Health Chicago Department of Public Health
Evelyn Norton	Patient Care Manager, NICU University of Chicago Hospitals
Suma Pyati, M. D.	Director of Neonatology John H. Stroger Hospital of Cook County
Marilyn Quinones	Director of High Risk Case Management Erie Family Health Services
Vivienne Dawkins, MS, CNM	Bureau Chief Illinois Department of Human Services
Gail Wilson, RN, MS, MPH	State Director March of Dimes
Nancy L.Maruyama,RN,NCBF Community	Executive Director, Education & Sudden Infant Death Services of Illinois, Inc
Richard Roderick	Master Sergeant

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Belinda Waller Division of Community Health and Prevention
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Division of Community Health & Prevention

Robert Sabich Illinois Department of Human Services

Staff

Carrie Wicks FIMR Coordinator

Benita Carpenter FIMR Outreach Coordinator

Cathy Gray Project Director

Appendix B:
Glossary of Terms, Diagnoses and Procedures

This appendix contains basic information to assist non-medical members of the case review team to understand common terms, diagnoses and procedures that they might encounter in review of individual cases

Please do not feel that these terms need to be memorized. Use this document as a dictionary and refer to it as needed. Experience tells us that after a year or so of reviewing cases, all team members will naturally come to an understanding of these terms, as well as others, without making any special effort.

Abruptio Placentae - A condition in which the placenta separates from the inner wall of the uterus before the baby is born.

AFP (also MSAFP) - See alpha-fetoprotein.

Active Labor - The stage of labor during which the cervix steadily dilates from 4 to 10 centimeters.

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Alpha-Fetoprotein - A substance, mostly fetal in origin, which can be found in elevated levels in the maternal blood serum with some abnormalities of pregnancy including open neural tube defects (NTD) of the fetus.

Amniocentesis - Involves obtaining a sample of amniotic fluid from the sac surrounding the fetus. The amniotic fluid contains fetal cells that can be analyzed for chromosomal and biochemical studies.

Amnionitis - See Chorioamnionitis.

Amniotic Fluid - water in the sac surrounding the fetus in the mother's uterus.

Amniotomy (AROM)- Artificial **r**upture **o**f the **m**embranes.

Analgesia - Relief of pain by loss of pain sensation, e.g. narcotics or regional anesthesia.

Antibiotics - Drugs that kill microorganisms that cause infection.

Anomaly - A malformation or significant deviation from the norm.

Anencephaly- A congenital malformation of the fetus in which the brain and skull do not develop above the brain stem.

Antibody - A substance that is produced by the body when exposed to infection or foreign materials and triggers a response to fight the infection or to destroy the foreign material .

Apgar Score - A measurement of a baby's response to birth and life on its own, taken at one and five minutes after birth.

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Apnea - failure to initiate breathing in a newborn or the cessation of breathing in an infant, child or adult.

Apnea Spells - Infant stops breathing for more than 20 seconds. Seen more commonly among sick or preterm infants.

Appropriate for Gestational Age (AGA) - The weight or a measurement of the fetus or infant falls between the 10th and 90th percentile based on the average of a large number of pregnancies of the same gestational age.

Auscultation - A method of listening to the fetal heartbeat, either with a special stethoscope or the use of an ultrasound device.

AROM - **A**rtificial **R**upture **o**f **M**embranes. See Amniotomy.

Atresia - Congenital absence or closure of a normal body opening or tubular structure.

Atypical - Development of abnormal cells.

Biophysical Profile (BOP) - A means of measuring fetal breathing, muscle tone, body movement and amount of amniotic fluid along with an NST to check on the fetus during labor.

Bishop Score - A scoring system indicating the likely success of inducing labor.

Bradycardia - Slow heart rate.

Breech - The positioning of the fetus's buttocks or feet presenting at the top of the birth canal instead of the fetal head.

Bronchopulmonary Dysplasia (BPD) - A chronic, progressive lung disease in infants that follows prolonged mechanical ventilation with high concentrations of oxygen.

C & S - Culture and sensitivity, as in a urine or blood specimen sent to the laboratory because of a suspected infection. The test will determine if infection is present, the type of bacteria or microorganism causing the infection and the antibiotic most likely to cure that particular infection.

Cephalo-Pelvic Disproportion (CPD) - A condition in which a baby is too large to pass through the mother's pelvis during delivery.

Chorioamnionitis - An infection of the membranes surrounding the fetus.

Colposcopy - Visualization of the cervix through the vagina for detection of abnormalities using a special microscope.

Congenital Disorder - a condition that affects a fetus before it is born.

Continuous Positive Airway Pressure (CPAP) - Delivery of oxygen-enriched air to the lungs under pressure. Oxygen, humidity and positive pressure help keep the air sacs (alveoli) open.

Cord Accident - Refers to a diminished or absent flow of fetal blood through the cord due to a knot in the cord, a very tight cord around the neck, etc.

CPAP - See Continuous Positive Airway Pressure.

Corticosteroids - High potency steroids which when given to the mother which may help to accelerate lung development in the fetus of less than 32 weeks gestation when labor and birth appears inevitable.

Diabetes - A condition in which levels of sugar in the blood are too high.

Down Syndrome - A genetic disorder caused by the presence of an extra chromosome (21) and characterized by mental retardation, abnormal facial features and medical problems such as heart defects.

DPT - combined **d**iphtheria, **p**ertussis and **t**etanus immunization.

Dubowitz Examination - A standardized physical examination of newborns that establishes their gestational age at birth.

Dysplasia - The development of abnormal tissue.

Dystocia - Difficult labor - a generic term that may be used to describe no progress or slow progress in labor.

Ecchymosis - A discoloration of the skin (a bruise) caused by leakage of blood into the tissues under it.

Ectopic Pregnancy - A pregnancy in which the fertilized egg begins to grow in a place other than inside the uterus, usually a fallopian tube.

Edema - Swelling caused by fluid retention.

Electronic Fetal Monitoring - A procedure in which instruments are used to record the heartbeat of the fetus and contractions of the mother's uterus during labor.

Estimated Date of Delivery (EDD) - Initially calculated using the date of the first day of the last menstrual period (LMP), subtracting 3 months and adding 1 year and 7 days.

ETOH - Ethyl alcohol.

Fetal Alcohol Syndrome (FAS) - A constellation of congenital malformations seen to varying degrees in infants born to mothers using alcohol during their pregnancy.

Fibroids - Benign smooth muscle growth on the inside of the uterus, on its outer surface, or within the uterine wall itself.

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Forceps - Special instruments placed around the baby’s head to help guide it out of the birth canal.

Gastroschisis - A congenital defect in the wall of the abdomen, which remains open at birth.

Gestational Diabetes - Diabetes that arises during pregnancy; it results from the effect of hormones and usually subsides after delivery (See Diabetes).

Gestational Age (GA) - The number of completed weeks of gestation elapsed from the first day of the last menstrual period and the date of delivery, irrespective of whether the gestation results in a live birth or fetal death. See also AGA, LGA and SGA.

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Glucose - A sugar that is present in the blood and is the body’s main source of fuel.

Glucose Tolerance Test (GTT) - A standardized blood test of glucose metabolism used to diagnose gestational diabetes (GDM).

HepB - Hepatitis B

Herpes Culture - A viral culture done late in pregnancy to diagnose shedding of Herpes II virus from the vulva, cervix or vagina.

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HIB - Haemophilus **i**nfluenza type **B** immunization.

HMD - See Hyaline Membrane Disease.

Human Chorionic Gonadotropin (hCG) - A hormone produced by the placenta; its detection is the basis for most pregnancy tests.

Hyaline Membrane Disease (HMD) - Acute respiratory disorder occurring shortly after birth, mostly in preterm infants, due to insufficient lung surfactant. Also known as respiratory distress syndrome (RDS).

Hyperbilirubinemia - Excessive levels of bilirubin (a break-down product of red blood cells) in the blood and tissues. Causes jaundice (yellow appearance) in the newborn and other problems.

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Incompetent Cervix - A weakened cervix due to inherent deficiencies, injury, etc., that results in repeated painless spontaneous abortions during the second trimester.

Insulin - A hormone that controls the levels of glucose (sugar) in the blood**.**

Insulin-Dependent Diabetes - Diabetes requiring insulin for control of blood sugar, usually occurs with juvenile or long-term diabetes and with onset prior to conception. See also Diabetes.

In Vitro Fertilization - A procedure in which the egg is removed from a woman's ovary, fertilized in a dish in a laboratory with the man's sperm, and then reintroduced into the woman's uterus to achieve a pregnancy.

Integument - Skin**.**

Intra-Uterine Growth Retardation (IUGR) - condition when the weight of a fetus or newborn is below the tenth percentile of mean weight for gestational age.

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Intrapartum - Time during labor and delivery**.**

Intraventricular Hemorrhage (IVH) - Hemorrhage from fragile blood vessels in the brain, especially in preterm infants.

Jaundice - A build up of bilirubin that causes a yellow appearance.

Karyotype - The chromosome pattern of an individual**.**

Kick-count - A record kept during late pregnancy of the number of times a fetus moves over a certain time period.

Laparoscopy - A surgical procedure in which a slender, light-transmitting instrument is used to view the pelvic organs.

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Large for Gestational Age (IGA) - The weight of the fetus is greater than the 90th percentile of all fetuses at the same stage in pregnancy. Macrosomia (greater than 4500 grams) is also a term used to describe large babies.

Last Menstrual Period (LMP) - The first day of the last menstrual period that the woman had before she became pregnant. Used to calculate gestational age.

Lecithin/Sphingomyelin Ratio (L/S Ratio) - Surfactant measurement determined by analysis of amniotic fluid usually obtained by amniocentesis. It is one way to evaluate fetal lung maturity in near term pregnancy. See also Phosphatidylglycerol.

Mascrosomia - A fetus or infant weighing more than 4500 grams. See also LGA.

Meconium Staining - Amniotic fluid stained by brownish-greenish substance that builds up in the bowels of the fetus and may be released in utero.

Methadone - A drug used to treat heroin addicts.

Microcephaly - An abnormally small head often associated with genetic disorders or congenital infections of the fetus.

MMR - combined measles, **m**umps, and **r**ubella immunization.

Multiple Pregnancy - More than one fetus, i.e., twins, triplets, etc.

MSAFP - See alpha-fetoprotein.

Necrotizing Enterocolitis - Bacterial invasion of the bowel wall which can lead to perforation. Predominantly seen in preterm babies, as a very serious complication.

Neural Tube Defect (NTD)- An defect in development of the brain or spinal cord (spina bifida, anencephaly). May be relatively mild to very severe. See also alpha-fetoprotein abnormality.

Non-Stress Test (NST) - A test in which fetal movements felt by the mother or noted by the doctor are recorded, along with concurrent changes in the fetal heart rate.

Oligohydramnios - A smaller than normal amount of amniotic fluid.

Omphalocele - Congenital hernia of the navel.

Oxytocin - A drug used to help bring on uterine contractions.

Oxytocin Challenge Test (OCT) - An assessment of fetal well-being measuring fetal heart rate with an external electronic monitor when the uterus is induced to contract by nipple stimulation or IV oxytocin. Also known as Contraction Stress Test (CST).

Pelvic Inflammatory Disease - Usually caused by a sexually transmitted infection of the female reproductive organs.

Persistent Pulmonary Hypertension of the Newborn (PPHN) - Constriction of pulmonary vessels in the newborn, which results in insufficient blood circulation to the lungs and may cause persistent fetal circulation (PFC).

Persistent Fetal Circulation (PFC) - Circulation of blood continues to follow the fetal pattern which results in inadequate oxygen supply for the newborn.

Persistent Ductus Arteriosus (PDA) - A condition in which an open vessel connecting the pulmonary trunk and aorta persists after birth, allowing for abnormal blood circulation.

Phosphatidylglycerol - A surfactant component of amniotic fluid which, when present, indicates a high likelihood of fetal lung maturity.

Placenta - Tissue that connects mother and fetus and provides nourishment to and takes away waste from the fetus.

Placenta Previa - A placenta that is implanted in the lower uterine segment and covers all or part of the cervical os.

Pneumomediastinum - Abnormal accumulation of air in the center of the chest cavity which reduces the return of blood to the heart.

Pneumothorax - Rupture of air sacs (alveoli) in the lung, which allows air into the chest cavity collapsing the lung.

Pudendal Block - an injection given in the perineum that relieves pain during delivery but not during labor.

Polydactly - Extra fingers or toes on a newborn.

Polyhydramnios - Greater than normal amount of amniotic fluid, often associated with some congenital anomalies or maternal diabetes.

Preeclampsia - high blood pressure during pregnancy. Severe pre-eclampsia may lead to seizures (called eclampsia).

Premature Rupture of Membranes (PROM) - Spontaneous rupture of the membranes at any time before the onset of labor.

Pyelonephritis - A kidney infection (with or without a concurrent bladder infection) which occurs more frequently in the second and third trimesters of pregnancy.

Respiratory Distress Syndrome (**RDS**)- See Hyaline Membrane Disease.

Rubella (German Measles) - A viral infection. The fetus of a mother infected in the first weeks of pregnancy may have multiple defects of the heart, eyes, ears, CNS and other organ systems.

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Sexually Transmitted Disease (STD) - Any infection spread during sexual contact. Includes AIDS, herpes, gonorrhea, syphilis, chlamydia, papilloma virus (genital warts) and a number of others.

Shoulder Dystocia - A problem during birth in which the head is born but the shoulders become wedged in the pelvis.

Small for Gestational Age (SGA) - The weight of the fetus is below the 10th percentile for fetuses at the same stage in pregnancy. SGA babies may occur as a result of abnormal placental function, cigarette smoking, infections, nutritional deprivation, genetic disorders or multiple gestations. See also IUGR.

Spina Bifida - A neural tube defect in the spinal column which may result in bulging membranes (meningocele) or bulging membranes and spinal cord (meningomyelocele) and sensory-motor dysfunction below the lesion.

Spinal Block - A form of anesthesia that numbs the lower portion of the body.

Spontaneous Abortion - A miscarriage prior to the 20th week of gestation.

Stenosis - The narrowing or stricture of a structure.

Stridor - Harsh sounds during respiration; high-pitched and like the blowing of the wind due to obstruction of air passages.

Sudden Infant Death Syndrome (SIDS) - The sudden death of a baby for no apparent reason.

Surfactant - A substance normally contained in the amniotic fluid near term or a pharmaceutical replacement drug instilled into the lungs of some at risk newborns to prevent RDS .

Syndactyly - Webbed or fused fingers or toes.

Tachycardia - Rapid heart rate.

T.E. Fistula - An open tract (fistula) connecting the esophagus and the trachea (must be surgically repaired).

Teratogens - Agents that can cause birth defects when a woman is exposed to them during early pregnancy.

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Tocolytic Agents - Any of a number of drugs used to try and suppress premature labor such as beta agonists (e.g., ritodrine and terbutaline) or magnesium sulfate.

TORCH - An acronym for the infections of **t**oxoplasmosis, **o**ther organisms or viruses, **r**ubella, **c**ytomegalovirus and **h**erpes simplex.

Transient Tachypnea of Newborn (TTN) - Very rapid respirations in newborns. Thought to be due to fluid in the lungs. Oxygen administration may help. Generally resolves in 36-72 hours without long-term problems.

Trimester - Any of the three 3-month periods into which pregnancy is divided.

Tubal Ligation - A method of female sterilization in which the fallopian tubes are closed by tying, banding, clipping or sealing with electric current.

Ultrasound - A test in which sound waves are used to produce images to examine the fetus or view internal organs**.**

Umbilical Cord - A cord-like structure that connects the fetus to the placenta**.**

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Urinary Tract Infection - An infection in the kidney or bladder or both.

Vacuum Extraction - The use of a special instrument attached by suction to the baby's head to help guide it out of the birth canal during delivery.

Definitions from the American College of Obstetricians and Gynecologists *Guide to Planning for Pregnancy, Birth and Beyond* 1990. pp. 247-250.