

*Atlantic City Healthy Start  
(HSI Infrastructure/  
Capacity Building)*

**FINAL REPORT & ABSTRACT**

Submitted by:  
Southern New Jersey Perinatal Cooperative  
2500 McClellan Avenue  
Pennsauken, New Jersey

June 30, 2001

**FINANCIAL STATUS REPORT**

See Standard Form 269A attached.

## **EQUIPMENT LISTING**

\*\*No equipment has been purchased for this project.

## FINAL REPORT

### PROJECT IDENTIFICATION

Project Title: Atlantic City Healthy Start (HIS  
Infrastructure/Capacity Building)

Project Number: H50MC00003-01

Project Director: Judy Donlen, DNSc, JD, MSN

Grantee Organization: Southern New Jersey Perinatal  
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Project Period: 7/1/99 - 6/30/00

Total Amount of Grant Awarded: \$150,000

NARRATIVE:

I. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V  
MATERNAL AND CHILD HEALTH (MCH) PROGRAMS:

The goal of the Atlantic City Healthy Start Project is to reduce the infant mortality rate in Atlantic City, especially in minority populations. The Atlantic City maternal and child health population is at an extreme disadvantage in receiving the care that is necessary for improving the health outcomes and quality of life of the community. Atlantic City's infant mortality cannot be attributed to a single or primary cause but is due to a complex mixture of biological, social and economic conditions, reflected by parental education, occupation, income and housing. A solution to the problem of infant mortality can only be found in community plans that address the many health and social issues surrounding family planning, prenatal care and primary pediatric care, as well as housing and environmental problems, education, employment and motivation.

The grantee organization, Southern New Jersey Perinatal Cooperative (SNJPC), is one of seven regional maternal and child health consortia. The MCH Consortia are regional affiliations of perinatal and pediatric providers, hospitals, community-based agencies and consumers which coordinate maternal and child health activities in seven regions covering the state. The SNJPC's general membership also includes representation from local social service agencies. SNJPC's status as a licensed MCHC and recipient of NJDHSS administered grant funds helps assure the success of the Atlantic City Healthy Start Project because of the collaborative relationships SNJPC maintains with divisions

within the New Jersey Department of Health and Senior Services including the Divisions of AIDS and Addictions, and with other state agencies, such as the Departments of Human Services, Education and Community Affairs. SNJPC has been active in Atlantic City for over a decade, providing staff support to collaborative efforts such as the Healthy Mothers Healthy Babies Coalition and securing funding for numerous new services through Title V funding, foundations and other sources.

The SNJPC and the Atlantic City Healthy Mothers Healthy Babies Coalition (the Project Area Consortium) are integrally involved with programs aimed at improving the health status of women and children in the project area and statewide. In Atlantic City, prenatal services are provided through two agency based prenatal clinics. Both of these providers are general members of SNJPC and have been active participants in the ACHMHBC since its inception. The involvement of SNJPC and ACHMHBC in statewide MCH activities has insured that the perinatal and childhood service needs identified in the FY 96 MCH Title V - Five Year Comprehensive Needs Assessment and Block Grant Plan reflect the information compiled in the SNJPC Perinatal and Pediatric Plan and the ACHMHBC annual workplans.

Because the approach to improved maternal and child health has historically been fragmented in Atlantic City, the focus of this project was on building better relationships and linkages between existing programs and agencies. The Atlantic City Healthy Mothers Healthy Babies Coalition oversaw the Healthy Start Consortium in improving and building upon its current relationships with currently existing agencies and programs. Particular attention was paid to building relationships with the local Medicaid and

Title V agencies. In addition, there was a commitment to engage diverse stakeholders throughout the decision making and project evaluation process. Community residents were involved throughout the project, as they have the biggest stake in changing community behavior and norms.

## II. GOALS AND OBJECTIVES:

The overall goal of the Atlantic City Healthy Start Project is to reduce the infant mortality rate, especially in the minority populations. The objective of the first phase of the Atlantic City Healthy Start Project was to conduct a full needs assessment to identify gaps and disparities in Atlantic City's delivery system. Upon completion of the full needs assessment, Atlantic City Healthy Mothers Healthy Babies Coalition (ACHMHBC) initiated a second phase to expand the current coalition to include all stakeholders in Atlantic City. A team, the Atlantic City Healthy Start Consortium, will be built to identify models and strategies that can be implemented to address the identified needs.

## III. METHODOLOGY:

The first phase of the project, the full needs assessment, consisted of data collection efforts that were focused on the provider and patient population. A variety of formats were used in the data collection: vital statistics, utilization and service reception data, statistical small area health analysis, local area provider assessments, target surveys and focus groups. Survey tools are included in the Appendix.

The second phase of the project addressed the problems illustrated by the full needs assessment through identification of effective health care delivery models and the development of comprehensive community initiatives through 1) formation of an expanded Healthy Start Consortium of health care providers, social services agencies, schools and local government; and 2) evaluation of health care delivery strategies designed to meet the health needs of the maternal and child population. Strategies that were evaluated and benchmarked for future implementation include case management and care coordination, home visiting programs, and current outreach projects.

#### IV. EVALUATION:

The Southern New Jersey Perinatal Cooperative conducted the necessary data collection and evaluation of the Atlantic City Healthy Start project. SNJPC has a perinatal database for the collection and analysis of data. Electronic birth certificates are used to increase the timeliness and accuracy of the state's birth information. SNJPC also provides specially trained staff to assist hospitals in the implementation and use of the Neonatal Information System, a computer program designed to track the course of an infant's treatment and outcome.

The evaluation involved an ongoing assessment of progress made in the planning process as well as final recommendations for strategies to be implemented. The primary objectives of the process assessment were to describe the interventions pursued by the various grantees, identify gaps and any subsequent problems encountered in integrating service coordination. The evaluation also

assessed the coalition's ability to implement partnership relationships. During the planning period, a database was created to aid in the collection of information on participant data and services planned to be implemented.

Data collection included:

- Vital statistics (birth and death records)
- Results of barrier surveys
- Process issues identified in focus groups
- Process issues identified by providers
- Client specific case management data

The process evaluation will continue throughout the duration of the grant. The Southern New Jersey Perinatal Cooperative will attend planning meetings of the project groups and provide technical assistance as appropriate.

#### V. RESULTS/OUTCOMES (POSITIVE & NEGATIVE)

The following progress has been made during the planning phase of the Healthy Start project for Atlantic City.

1. A database of all stakeholders both consumers and providers has been developed. This was further enhanced by adding those interested consumers who were focus group participants.
2. Timelines to track the development of the Healthy Start Consortium have been established with the key members of the current Healthy Mothers Healthy Babies Coalition.
3. A data subcommittee of the Healthy Start Consortium was established to oversee the implementation of tracking the health outcomes data, specifically as a fetal-infant mortality review process utilizing the "periods of risk" model to perform causal analysis.

4. A plan to organize the Healthy Start Consortium, identify the target population, outline the needs and track the interventions by assigned agency was developed.
5. An evaluation subcommittee was formed to oversee the project and track the progress towards all established goals.
6. The database was enhanced by the addition of key elements not currently cohorted for city residents by race/ethnicity. This data became available from the Center for Health Statistics of the New Jersey State Department of Health and Senior Services.
  
7. The Southern New Jersey Perinatal Cooperative is currently the manager of the Service Bureau for the New Jersey Immunization Information System in the city of Camden (Immunization Registry). The Southern New Jersey Perinatal Cooperative has implemented this service in Atlantic City in order to coordinate immunizations given in all private and public pediatric and family practice locations.

#### DATA ANALYSIS

Despite the small size of Atlantic City, it is challenged with the social, health, technical, political, economical, and legal challenges that confront the major cities of this country. The city's statistics reflect a national pattern of poor access to primary and preventive care, in which individuals with low incomes and members of racial and ethnic minorities suffer from high rates of disease and death while living in urban areas abundant in health care resources.

Atlantic City perennially ranks number one in the county and in the top five statewide with regard to indicators of poor access to care, such as babies born with low birth weights, teen pregnancy, high infant mortality rates, WIC, affirmative action, and low immunization rates. To further exacerbate the problem, there is a lack of providers within the city. As a result, Atlantic City has been designated a Health Manpower Shortage Area and Health Professional Shortage Area. The population at risk is disproportionately large relative to the size of the city. There is a great need to improve the provision of maternal and child health care services to the citizens of the community, as evidenced by the many indicators listed below.

a) **Project Area Demographic Data**

1. Geographic Description

Atlantic City is a small city in southeastern New Jersey that is approximately 46 blocks long and nearly a mile wide. Its land area totals 11.35 square miles. Atlantic City is the financial and social hub of South Jersey and is positioned virtually at the center of the Northeastern corridor of the United States. This convenient location has made it an ideal location for the development of the casino and hospitality industry. Prior to the development of the gaming industry, Atlantic City was a family resort and much of the employment in the city was in low-skilled, seasonal service jobs. The initiation of casino gaming was preceded by hopes that much of the low-income population would be revived by well paying jobs. However, this was not the case and many local residents

remain unemployed, underemployed, or unemployable. In 1997, the average unemployment rate for Atlantic City was 12.7%.

Atlantic City accounts for 16% of the total population of Atlantic County. The 1990 census enumerated a population of 37,986 year round residents within Atlantic City. This equals approximately 3,350 persons per square mile. Taking into account the 33 million visitors a year and nearly 50,000 workers a day, the city is one of the most densely populated in the country. While the total population decreased by about 5 percent from the 1980 population, this trend has reversed course so far in the 1990s. The city's population rose to an estimated 38,361 as of July 1, 1996, an increase of 375 from the 1990 Census level.

Of the 37,986 residents in 1990, 19,094 (50%) were Black non-Hispanic, 11,699 (31%) were white non-Hispanic, 5,566 (15%) were Hispanic, and 1,396 (4%) were Asian or Pacific Islander, with the remainder representing other population groups. There have been some significant shifts in the city's racial makeup between 1980 and 1990. In 1980, 46 percent of the city's population was white (including Hispanics) compared with 35% in 1990. The city's African American population remained relatively stable, declining by only 538 or 2.7 percent. Offsetting these losses were a six-fold or 1,256 increase in the Asian and Pacific Islander category, and a 2,083 or 167 percent jump in the other category. Another notable shift occurred in the number of Atlantic City residents who are of Hispanic origin, which more than doubled in the ten-year interval.

## 2. Population

According to the 1990 census, the total number of women of childbearing age is 8,377. This subpopulation accounts for 22% of the population in Atlantic City. Of the women of childbearing age, 4,859 (58%) were African American, 2,247 (27%) were white, and 298 (4%) were Asian or Pacific Islander, with the remainder representing other population groups. Hispanic women of childbearing age account for 18% of the population (1,466), however this number is not exclusive of the racial breakdowns above. Of interest is the fact that minority populations are even more prevalent in the population of women of childbearing age than the general Atlantic City population. In 1990, 35% of the Atlantic City population was white (including white Hispanics), while only 27% of women of child bearing age were white. In the general population, African Americans accounted for 52% of the population versus 58% for women of childbearing age, and Hispanics accounted for 15% versus 18%, respectively.

### 3. Behavioral and Environmental Factors

Many residents of Atlantic City are living amidst extreme social and economic conditions. Risk factors that are prevalent within Atlantic City include low immunization rates, substance abuse, child abuse and neglect, and poor living environments.

Surveys of immunization in Atlantic City have revealed difficult situations. A review conducted in 1995 by the New Jersey Department of Health and Senior Services revealed that the immunization rates were at 47-65% of age appropriate coverage. An assessment done in 1998 on a sample of children being tracked for immunization visits at an Atlantic City pre-school indicated that 64.3% were

appropriately immunized. Despite the low immunization rates, the barrier free child immunization project in Atlantic City lost grant funding for 1999, and has had to cut back the numbers of days and hours that the clinic operates, thus threatening to leave even more children improperly immunized.

Child abuse and neglect is another substantial problem in Atlantic City. In 1997, there were 132 instances of substantiated child abuse in Atlantic City. These cases accounted for 41% of the total in Atlantic County. There were 130 reported cases of family problems, representing 29.3% of the total for this category in Atlantic County. The number of family problems is up from 86 in 1996, representing an increase of 44 cases.

There are a significant number of housing units in Atlantic City (approximately 13,500) which are unsuitable with lead based paint. Nearly 2,200 children are either directly exposed or are at a high risk of potential lead poisoning.

#### 4. Poverty Level

Poverty is high in Atlantic City. While employment in the county jumped with the infusion of casino dollars, many of the jobs created were in the lower paying job brackets, such as hotel work and food service. Also, the economy of the casinos is seasonal; winter slumps contribute to the sagging growth, and many employees are laid off in the winter. The city has not benefited as it anticipated it would with the arrival of the casino industry. Rather, dollars from tourists and employees are concentrated at the casinos themselves; the money does not seem to have disseminated out into the surrounding community.

Many local residents remain unemployed, underemployed, and unemployable. Jobs have gone to suburbanites and the middle class has fled to neighboring communities. Many residents lack high school or equivalency training, and a significant part of the population can not access casino related employment or public sector jobs because of past criminal records and ex-offender policies. As of 1991, the New Jersey Casino Control Commission reported that of the approximately 46,700 jobs created by the gaming industry, only 11,000 (23.5%) were held by Atlantic City residents.

The median household income in 1989 was \$20,309. Almost twenty five percent of all city residents lived below the poverty line. This number includes 40% of all children under the age of 18 and 60% of female-headed households living below the poverty level. For female householder families with children under age five, 58% lived below the poverty level. The 1990 census data also showed that nearly half (46%) of the population of Atlantic City lived at or below the 200% level of poverty. In 1998, according to Kids Count New Jersey, 1,882 children in the city received AFDC/TANF benefits, accounting for more than half of the County's children who received the benefits. In the same year, 2,895 children received food stamp benefits, accounting for half of all children in the county who received food stamps. For the 1997-98 school year, 5,329 children received free or reduced price school lunches, accounting for 75% of all students in Atlantic City.

##### 5. Maternal Educational Level

Forty-one percent of the total population in Atlantic City aged 18 and over did not receive a high school diploma and only 9% received a bachelor or masters degree.

Educational attainment levels broken down by age and gender were unavailable for Atlantic City. Assuming that the sex and age breakdowns of the population of women of childbearing age were distributed similarly to that of the general population, it can be estimated that approximately 3,500 women of child bearing age have not finished high school.

**b) Perinatal Measures**

1. Birth and Death Rates

New Jersey's most recent Title V needs assessment (1996) identified disparate health conditions for minorities, especially Black infant mortality, as the main problem area in New Jersey. Other identified needs within the state include the reduction of teen pregnancy, an increase in healthy births, and a reduction of barriers to care. These identified areas are consistent with the problems that residents of Atlantic City are currently experiencing. Upon review of the maternal and child health statistics in Atlantic City, it is very obvious that the numbers reflect the urban health problems that are often seen in large cities. Information regarding births and birth outcomes in Atlantic City suggests that children, and in particular infants, are at high risk for poor health status.

While data from 1993, 1994 and 1995 were utilized to calculate a three year average for the initial grant application, 1996 data has since become available. Therefore, the three-year average utilized in the following descriptions is for the years 1994, 1995 and 1996. In addition, provisional data for 1997 has been obtained from

the New Jersey Department of Health and Senior Services, Division of Family Health Services. However, since the official natality data from the Center for Health Statistics is not yet available, the 1997 data will not be incorporated into the rolling three-year average.

The number of live births in Atlantic City totaled 943 in 1994, 856 in 1995, and 755 in 1996. Over the three years, the average number of births per year was 851. The provisional data for 1997 shows that there were 755 births in 1997. On the average over the same three years, 49% of the births were Black and 33% of the births were Hispanic.

**Resident Live Births**

Region	Total Births 1996	Total Births 1995	Total Births 1994	3-Year Average
Atlantic City	755	856	943	851
New Jersey	114,335	114,905	117,684	115,641

*Source: New Jersey Department of Health and Senior Services, Center for Health Statistics.*

An important indicator for infant and child health is the incidence of births to teens. Children born to adolescents are more likely to be of low birth weight, to have health problems, and suffer child abuse and neglect. Additionally, adolescent parents have fewer educational and career opportunities, thus perpetuating poverty for themselves and their children. Teen pregnancy is a significant problem in Atlantic City. A total of 509 babies were born to mothers under the age of 18 in Atlantic City between 1994 - 1996. This accounts for 20% of the total births in that time period. In comparison, 7.8% of

all births were to teens in New Jersey between 1994 - 1996. Very few women with children in the teen population are married, signaling that these women are most likely at risk for heading into the cycle of poverty. On the average, 69% of all women who gave birth between the years of 1994 - 1996 in Atlantic City were unmarried.

**Maternal Characteristics of Births**

Year	Percent Births to Teens (< 20)	Percent Births to Unmarried Mothers	Percent Births to Whites	Percent Births to African-Americans	Percent Births to Hispanics
1994 A.C.	20.1%	70.49%	40.62%	53.05%	27.86%
1995 A.C.	22.4%	68.79%	43.36%	49.47%	32.59%
1996 A.C.	16.8%	68.6%	43.4%	44.0%	38.0%
A.C. Average	20%	69%	42.3%	49.2%	32.5%
N.J. Average	7.8%	27%	74.7%	18.8%	16.1%

*Source: New Jersey Department of Health and Senior Services, Division of Family Health Services.*

Low birthweight infants (infants born weighing less than 2,500 grams, or about 5.5 pounds) are at higher risk of death or long-term illness and disability than are infants of normal birthweight. In 1996, the average percent of infants born of low birthweight throughout the United States was 7.4%. In New Jersey, low birthweight babies accounted for 7.4% of live births between 1994 - 1996. In Atlantic City, low birth weight babies (<2,500 grams) are much more prevalent than in New Jersey and the United States. Between 1994 - 1996, an average of 9.2% of all live births had a low birth weight. The provisional data for 1997 shows an increase of low birth weight babies to 10.7%. Additionally, between 1994 - 1996, about 2% of

infants were born with very low birthweights (less than 1,500 grams) in Atlantic City. This percentage also increases in 1997, to 3.4%.

The increase in low birthweights is associated with risk factors such as substance abuse, adolescent pregnancy and inadequate prenatal care. Furthermore, technological and medical advances have allowed many extremely premature infants who a few years ago would have died prior to delivery to be born alive. Another significant reason for the increase in low and very low birthweight babies over the past several years is that the number of twin, triplet and higher-order multiple births has increased. Twins and other multiples are much more likely than single infants to be of low birthweight. The percentage of multiple births in Atlantic City was much higher in 1998 for babies weighing less than 1,500 grams (14%) than the percentages seen in babies weighing more than 1,500 grams (3%), according to the *Report of the Regional Collaborative Database* published by the Southern New Jersey Perinatal Cooperative in 1998.

#### **Low Birth Weight Births**

Year	< 2,500 grams	< 1,500 grams
1994 A.C.	9.15%	2.34%
1995 A.C.	8.57%	1.88%
1996 A.C.	10.1%	1.75%
A.C. Average	9.2%	2%
N.J. Average	7.4%	1.5%

*Source: New Jersey Department of Health and Senior Services, Center for Health Statistics. New Jersey Health Statistics 1996, February 1999.*

Infant mortality is defined as the death of an infant before his or her first birthday. The infant mortality rate is an important measure of the well being of infants, children, and pregnant women. Infant mortality is associated with a variety of factors, such as maternal health, quality and access to medical care, socioeconomic conditions, and public health practices. In the United States, about two-thirds of infant deaths occur in the first month after birth and are due mostly to health problems of the infant or the pregnancy, such as preterm delivery or birth defects. About one-third of infant deaths occur after the first month and are influenced greatly by social or environmental factors, such as exposure to cigarette smoke or access to health care (*America's Children: Key National Indicators of Well-Being* 1999).

The 1996 infant mortality rate for the United States was 7.3 deaths per 1,000 births. The infant mortality rate in New Jersey between 1994 - 1996 was 7.1 infant deaths per 1,000 live births. The average infant mortality rate over the same three years (1994 - 1996) in Atlantic City was 16.2. This is 2.3 times the rate seen in New Jersey.

While infant mortality has dropped for all race and ethnic groups over time on a national scale, there are substantial racial and ethnic disparities in infant mortality. In 1996, the infant mortality rate for white non-Hispanic, African-American non-Hispanic and Hispanic populations were 6.0, 14.2, and 6.1, respectively. The same disparities can also be seen on a state level. In 1996, white and African-American rates were 5.3 and 14.9, respectively, in New Jersey.

Like the rest of the state and nation, there are great racial disparities in infant mortality in Atlantic City. The infant mortality rate averaged 27.0 for African-Americans compared to 5.7 for whites during the three-year period 1994-1996. Therefore, the infant mortality rate in Atlantic City for the years 1994 - 1996 was almost five times greater for African-Americans than for whites. Hispanics also had a much higher infant mortality rate, averaging 14.7 over the same three years.

**Infant Mortality Rates, by Race**

County/Large Municipality	Infant Mortality Rate (IMR)	IMR* White	IMR* African-American	IMR* Hispanic
1994	19.1	2.64	32.32	7.6
1995	17.5	5.42	30.88	3.6
1996	11.9	8.98	17.9	3.5
A.C. Average	16.2	5.7	27.0	14.7
N.J. Average	7.1	5.6	15.0	6.4

*Source: New Jersey Department of Health and Senior Services, Birth and Death Certificate Files. \* = Rates are computed per 1,000 live births.*

The neonatal period encompasses the first 27 days of life. Between 1994 - 1996 New Jersey averaged a neonatal infant mortality rate of 4.9 per 1,000 live births. In Atlantic City for the same time period the neonatal infant death rate averaged 11.49, which is more than double the state average. Again, these rates become even more disparate when broken down by race. The average neonatal mortality rate during the same three-year period was 20 for African-Americans compared to 3.8 for whites. Therefore, the neonatal mortality rate in Atlantic City for the years 1994 - 1996 was more than five times greater for African-

Americans than whites. Hispanics also had a slightly higher neonatal mortality rate, averaging 4.4 for 1994 - 1996.

**Neonatal Mortality Rates, by Race**

County/Large Municipality	Neonatal Mortality Rate (NMR)	NMR White	NMR African-American	NMR Hispanic
1994	13.77	0	24.24	0
1995	12.9	5.42	23.75	9.6
1996	7.8	6.0	11.9	3.5
A.C. Average	11.49	3.8	20.0	4.4
N.J. Average	4.9	4.1	9.6	4.5

*Source: New Jersey Department of Health and Senior Services, Birth and Death Certificate Files. \* = Rates are computed per 1,000 live births.*

**2. Perinatal Behavioral Risk Factors**

As demonstrated in the above data, pregnant women are not receiving adequate prenatal care in Atlantic City. Between the years of 1994 - 1996, the number of pregnant mothers who received prenatal care starting with their first trimester was 1,360 of 2,552 total births. This represents an average of only 53% of pregnant mothers receiving prenatal care in their first trimester. In the same time period, 49 women did not receive any prenatal care at any time during their pregnancy. This accounts for approximately 2% of all births, compared to 1.2% for the entire state.

**Births by Onset of Prenatal Care**

Year	Onset of Care in 1 <sup>st</sup> Trimester	No Prenatal Care Received
1994 A.C.	45.77%	1.9%
1995 A.C.	53.58%	1.05%
1996 A.C.	63.1%	2.91%

A.C. Average	53.55%	2%
N.J. Average	74.19%	1.2%

*Source: New Jersey Department of Health and Senior Services, Center for Health Statistics. New Jersey Health Statistics 1996, February 1999.*

#### EXISTING PROVIDER SYSTEM

There are a limited number of private providers within the city limits of Atlantic City. Most of the physicians are associated with the hospital and many maintain their offices within the hospital facility, particularly the specialists. The specialists have very limited hours of operation.

#### Surveys

Specific targeted surveys were utilized to assess the community in accordance with the plan and as part of the comprehensive community needs assessment. Samples of the tools used to obtain each survey are contained in the Appendix.

#### Consumer Needs Assessment:

The consumer needs assessments were aggressively distributed for input by the community. The following groups participated in completing the surveys:

- All focus group participants (five focus groups)
- Patients at the Reliance Medical Center
- Patients at the Dental Clinic
- Patients at Dr. Blair Bergen's office

Most of the respondents were consumers who were approached while receiving services or care. Thirteen of the surveys were completed by the members of the Healthy Mothers Healthy Babies Coalition following their focus group meeting. The surveys are fully summarized below and then the results of the Coalition are addressed separately also. This was done because the majority of the Coalition members represent service organizations and a smaller number are consumers who have actively participated on the Coalition for a number of years. This gives these consumers a level of sophistication regarding knowledge of the health care system that the other consumers did not have. A fuller analysis of the results is contained in the Appendix.

*Total Results of the Surveys:*

In total, there were 54 Needs Assessment Surveys completed by Atlantic City residents on nine different dates and locations. Of the total population, 47 or 87% were female. The majority of survey responders were African-American (52%), with the remainder of the population being Hispanic (30%), white (11%), Native American (4%), Asian (2%) and other (2%). There was quite a bit of variation in the age of responders, with the 25-34 age range representing the largest percentage of responders (32%).

The survey responders were also asked to report which of the factors listed were problems in their schools. As can be seen below, poor educational programs and lack of funding and resources were identified as the most commonly reported problems, with inattentive teachers and lack of student discipline tying for third. Again, all of the problems listed were reported to be a problem by at least

some of the responders, with unsafe buildings being reported the least often.

The next question inquired about the type of problems that each responder personally faced. The most commonly reported problems included inadequate financial resources, disease/illness/injury, and lack of spousal/family support (as denoted by the asterisk in the table below). Each of the problems listed were reported by at least some of the responders. The least commonly reported problem was having no place to live, reported by only four responders.

Another purpose of this survey was to identify how and why residents of Atlantic City seek help for their problems and if they do not seek help, what the barriers are to their seeking help. Other than family or friends, survey responders reported they would seek help most often from church clergy, family physicians and mental health counselors or clinics if they were having a serious personal or family problem.

Seventy four percent of responders revealed that they would seek help with a personal or family problem from a counseling agency. Of the 12 people who reported that they would not seek help from a counseling agency, the most common reasons for not doing so included not speaking English, the cost of services, and other unlisted reasons. Other reasons reported included lack of childcare, lack of faith in counseling therapy, embarrassment, religious/cultural beliefs prohibit it, and lack of knowledge of location of agencies. The fear of what others will think, lack of transportation, and inconvenient agency locations and hours were not reported as barriers to receiving counseling.

Survey responders were asked to select what they perceived as the three most serious problems in their community. The top three problems, as indicated by asterisks in the table below, included births to teens, children on welfare, and family problems. Every problem in the list was selected at least once. The problem least commonly reported was low birth weight.

Needs Assessment responders were then asked to indicate which services might be helpful in addressing the problems that were previously identified. The most commonly chosen responses included community parenting education, better educational programs and increased crime prevention and awareness. Each of the services were selected by at least 17 survey responders.

According to the Needs Assessment survey, responders were familiar with many of the agencies in Atlantic City. Responders were most familiar with Martin Luther King Family Center, Atlantic Human Resources and the Institute for Human Development. Responders were least familiar with the Family Development Program and UMDNJ.

Of the services that the agencies provide, the survey responders were asked to indicate which they thought should be expanded. All of the services were selected by at least 10 responders. The services most frequently selected included housing services, health, including prenatal and dental, and employment services. Under the health category, several responders indicated by writing on the survey that dental care was of particular concern.

Of the 36 people who reported that they have heard of the Family Center, 15 reported that they had used its services in the past. Nineteen people reported that they were satisfied with the services they received, even though

only 15 people reported utilizing the services. One person reported being unsatisfied with the services that he or she received. The survey responders indicated that all of the issues listed below could be improved at the agencies, with hours of operation the most commonly chosen.

*Subgroup Survey Results (Healthy Mothers Healthy Babies Coalition):*

On November 18, 1999, thirteen surveys were completed by the Healthy Mothers Healthy Babies (HMHB) Coalition following their focus group. The group was made up of mostly providers but also had some consumers. The survey responders consisted of 11 females and 2 males. Eleven of the survey responders were African-American, one was white and one was Hispanic. The ages of the responders was well distributed, with five falling into the 25-34 age category, 4 falling into the 35-44 age category, and 4 into the 45-54 age category. Five of the responders in this group were single, four were married, and four were divorced.

Eight of the HMHB survey responders reside in single family dwellings, four reside in apartments, and one reported living in a residence that fell into the "other" category. Five people reported residing in their current residence for 1-4 years. Two people reported residing in each of the remaining categories (under 1 year, 5-9 years, 10-14 years, and over 15 years). None of the responders reported living with a child under the age of five. Five people reported living with one child and two people reported living with two children in the 5-10 age group. For the 11-15 year old age group, five responders reported living with one child and one responder reported living

with two children. Three responders reported living with one teenager in the 16-18 year old age range. Seven responders reported living with one person that is 19 years of age or older and six responders reported living with two people 19 years of age or older. Again, there seemed to have been some confusion with this question, as some responders included themselves in this count while others did not.

The problems that the responders in the HMHB group perceived as existing in their community most commonly included crime/violence and drug dealers. Only one person reported that he or she felt pollution was a problem and nobody chose proximity to work/industry as a community problem.

The survey responders were also asked to report which of the factors listed were problems in their schools. As can be seen below, poor educational programs and inattentive teachers were most commonly reported as problems. Again, all of the problems listed were reported to be a problem by at least some of the responders.

The most commonly reported problems personally affecting the responders within the last five years included inadequate financial resources, lack of spousal/family support, and difficulty obtaining health care. None of the responders reported drug/alcohol addiction, unplanned pregnancies, or victim of crime/violence as problems.

Four survey responders reported they would seek help from church clergy and four responders reported they would seek help from family physicians. Three responders reported that they would seek help from mental health counselors or clinics and three reported that they would

seek help from another unlisted source. One person reported that he or she would seek help from a governmental agency and one at the hospital.

Eight responders revealed that they would seek help with a personal or family problem from a counseling agency. Of the five people who reported that they would not seek help from a counseling agency, reasons for not doing so included embarrassment, the cost of services, lack of faith in counseling therapy, religious/cultural beliefs prohibit it, and other unlisted reasons. The fear of what others will think, lack of transportation, not speaking English, inconvenient agency locations and hours, and not knowing where the agencies are were not reported as barriers to receiving counseling.

The top three most serious problems in the community, as indicated by asterisks in the table below, included juvenile arrests, infant mortality, births to teens, and family problems. Children receiving food stamps, low birth weight and teen death were not selected by anybody as one of the top three problems in the community.

The most commonly chosen methods for addressing the community problems previously identified included community parenting education, better educational programs and additional health care providers and/or clinics. Each of the services were selected by at least one survey responder.

According to the Needs Assessment survey, responders were familiar with many of the agencies in Atlantic City. All thirteen responders reporting being familiar with Martin Luther King Family Center, Atlantic Human Resources and the Institute for Human Development. Responders were

least familiar with the Family Development Program and UMDNJ.

Of the services that the agencies provide, the survey responders were asked to indicate which they thought should be expanded. All of the services were selected by at least one responder. The services most frequently selected included housing services, health, including prenatal and dental, and economic assistance. The services selected least often included parenting education and recreation.

#### Provider Surveys:

The provider surveys were distributed and completed by all public providers of prenatal care, WIC, well child and immunizations services, the hospital providers and six private prenatal providers as well as three private pediatric providers located in the city.

Of the private providers, less than half accept Medicaid fully but more than half did use a sliding fee scale for indigent patients who do not qualify for Medicaid. Use of the sliding fee scale was unrelated to Medicaid services.

Three prenatal providers and all of the pediatric providers offer some Saturday hours but none offer evening services. WIC does not offer any evenings or Saturday hours which presents a problem for teen mothers and conflicts with their school schedules. None of the providers identified a longer wait time than two weeks.

The racial/ethnic distribution of Atlantic City clients seen is primarily African American (more than 50% on average) and Hispanic. Only one private provider identified an Asian clientele in their patient population

exceeding 20%. Most patients access city services using public transportation.

The providers identified the following as the greatest barriers to adequate health care:

- Lack of insurance
- Lack of facilities and medical personnel
- Clients lack of knowledge and patients' not giving a high priority to obtaining health care

#### Barriers to Care Surveys:

These surveys are extremely comprehensive, resource-intensive, and limited to being appropriate for only those women who had just delivered. Therefore, the surveys were completed on postpartum women at Atlantic City Medical Center—City Division. Only a limited number of women (eight) consented to participate in the survey.

#### *Socioeconomic Indicators*

All eight of the mothers surveyed either had Medicaid prior to getting pregnant or were able to qualify during their pregnancy. However, one of the mothers reported that she was only covered for one month of her pregnancy. Two mothers reported that they had to go to the welfare office once to apply. Five mothers reported that they had to go to the welfare office three times. One mother reported having to go to the welfare office four or more times. One mother felt that the personnel at the welfare office were very helpful, three mothers felt that they were somewhat helpful, and four mothers did not think they were helpful at all. Of the people who felt that the welfare personnel were not helpful, two reported that they had a bad

attitude, two reported that they didn't speak their language, and two felt that they did not explain the forms.

#### *Perinatal Indicators*

Four of the mothers surveyed reported that this was their first pregnancy. Of the others, one reported that she had two other children. Another reported that she had four children born alive, however only three were still living. One of this woman's children weighed less than 5.5 lbs. at birth. Another mother reported that she had five other children, in addition to having two induced abortions and one miscarriage. Two of her children were born under 5.5 lbs. The last mother had eight children previously in addition to one induced abortion.

Of the eight mothers surveyed, six reported that they had no complications of pregnancy. One mother reported having anemia and one reported having diabetes and genital herpes as complications of pregnancy. Two people reported having a history of anemia before they got pregnant. Five mothers reported that they had ultrasounds and fetal monitoring performed on them during pregnancy. One of the mothers reported having an amniocentesis and two mothers had no obstetric procedures performed on them.

#### *Prenatal Care*

Two women thought they might be pregnant in their first month, three women first thought they might be pregnant in their second month, two women first thought they might be pregnant in their third month, and one woman did not think she might be pregnant until the third trimester. One woman reported that she thought she was pregnant due to a missed or change in period. Five women

noted that nausea led them to think that they were pregnant and two women reported that sore breasts made them think that they were pregnant. One person found out by taking a home pregnancy test.

### *Infant Care*

Two women reported that their babies have not had a check-up with a pediatrician since birth. One reason given for this was that the mother lost her insurance coverage. The other mother did not give a reason. Of the women who did bring their babies to the pediatrician, two drove them to the doctor, two reported using the bus, one took a taxi, one walked and one had a friend drive them.

### Focus Groups

There were five focus groups conducted in Atlantic City for a total of 50 participants.

Project Teach (teen moms)

10/18/99

Young Fathers (Uptown Center) 10/19/99

Grandparents (Stanley Holmes Village) 11/2/99

Spanish Community Center 11/17/99

Healthy Mothers/Healthy Babies Coalition 11/18/99

Each focus group was asked the same five questions for discussion:

1. What do you think when you hear the phrase, "Healthy Start?"
2. What do you think when you hear the phrase, "Healthy Mothers/Healthy Babies Coalition?"

3. What do you see as the major concerns or issues of infant and child health in Atlantic City?
4. What are the barriers to your use of healthcare services in Atlantic City?
5. What kind of healthcare services would you like to see be made available in Atlantic City?
6. What would encourage you to take action or get more involved in health care issues in Atlantic City?

In addition, a majority (90%) of the participants completed consumer needs assessments. Outreach to maximize participation in the focus groups was done in city shelters, food stores, laundromats, housing projects, churches, day care centers, senior centers and TANF training sites.

Of the 50 participants, 38 were female--25 were African American, 5 White and 8 Hispanic. Of the 12 male participants, 9 were African American, 1 White and 2 Hispanic.

The Healthy Mothers Healthy Babies Coalition of Atlantic City represented providers in service agencies within the city, for the most part. However, there were a small number of consumers who are also members of the Coalition; but, by and large, these are consumers who are more sophisticated about accessing the health care system and the issues related to maternal and child health care.

#### Results:

1. *What do you think when you hear the phrase, "Healthy Start?"*

WITH THE EXCEPTION OF THE PARTICIPANTS IN THE HEALTHY MOTHERS HEALTHY BABIES COALITION FOCUS GROUP, NONE OF THE OTHER PARTICIPANTS WERE FAMILIAR WITH THE PHRASE HEALTHY START OR THE PROJECT. HOWEVER, A LARGE NUMBER RESPONDED POSTIVELY THAT THEY WOULD BE WILLING TO PARTICIPATE IN HEALTHY START PROJECT DEVELOPMENT.

*2. What do you think when you hear the phrase, "Healthy Mothers/Healthy Babies Coalition?"*

ALL OF THE FEMALE PARTICIPANTS WERE FAMILIAR WITH THE HEALTHY MOTHERS HEALTHY BABIES COALITION OF ATLANTIC CITY AND SOME OF THEIR SPECIFIC PROJECTS. ONLY ONE MALE PARTICIPANT SEEMED COMFORTABLE WITH KNOWLEDGE OF THE GROUP. ALL OTHERS WERE VAGUE AND NOT SURE OF THE COALITION OR WORK.

*3. What do you see as the major concerns or issues of infant and child health in Atlantic City?*

□ GENERAL PROVIDER ISSUES

- LACK OF ENOUGH PROVIDERS IN THE CITY IN GENERAL
- LACK OF PROVIDERS IN THE CITY WHO ACCEPT MEDICAID
- APPOINTMENTS DIFFICULT TO OBTAIN
- HOURS UNCLEAR
- NO FOLLOW UP WITH TREATMENT
- INCONSISTENT CARE—LACK OF CONTINUITY WITH SAME PROVIDERS
- LACK OF PROVIDER SENSITIVITY
- LACK OF DENTAL CARE AVAILABILITY
- LACK OF VISION CARE AVAILABILITY

➤ LACK OF SPECIALTY CARE WITH CONSISTENT ACCESSIBLE HOURS IN THE CITY

- ❑ LACK OF REIMBURSEMENT FOR PRESCRIPTIONS
- ❑ LACK OF EDUCATION ACCESS FOR TEEN MOMS
- ❑ HOSPITAL SERVICES INCONSISTENT AND INSENSITIVE FOR PEDIATRICS AND IN THE ER

*4. What are the barriers to your use of healthcare services in Atlantic City?*

- ❑ LACK OF INSURANCE
- ❑ ELIGIBILITY CRITERIA UNCLEAR
- ❑ NJ KIDCARE BUREAUCRACY—DIFFICULT TO OBTAIN
- ❑ TRANSPORTATION
- ❑ LANGUAGE BARRIERS
- ❑ LACK OF CHILD CARE
- ❑ PROVIDER SENSITIVITY
- ❑ EMERGENCY ROOM AT THE HOSPITAL IS "UNCLEAN" AND STAFF ARE HOSTILE TO PATIENTS.

*5. What kind of healthcare services would you like to see be made available in Atlantic City?*

- ❑ DENTAL AND VISION SERVICES
- ❑ MORE PEDIATRIC AND PRENATAL PROVIDERS
- ❑ SERVICES THAT ARE MORE CULTURALLY SENSITIVE AND ACCESSIBLE IN TERMS OF HOURS OF AVAILABILITY
- ❑ MORE TEEN ACTIVITIES
- ❑ PARENTING SKILLS EDUCATION
- ❑ EDUCATIONAL SERVICES THAT ARE WELL PUBLICIZED AND EASY TO ACCESS SUCH AS CHILD BIRTH CLASSES

- ❑ AFFORDABLE HOUSING AND SHELTERS FOR THE HOMELESS
- ❑ POSITIVE EDUCATION TO DE-EMPHASIZE DRUGS AND VIOLENCE

6. *What would encourage you to take action or get more involved in health care issues in Atlantic City?*

- ❑ INVOLVEMENT IN A PROJECT WITH A CLEARLY OUTLINED OBJECTIVE AND OUTCOMES THAT GET ACHIEVED
- ❑ MORE JOB TRAINING AVAILABILITY AND GED SITES
- ❑ MORE EDUCATIONAL OPPORTUNITIES SUCH AS ENGLISH AS A SECOND LANGUAGE COURSES

### Gap Analysis

Health outcomes for Atlantic City continue to be dismal in comparison to the county, the state and the nation as a whole. The top three issues of concern in Atlantic City as identified by providers and consumers alike in surveys and focus groups are:

- Infant mortality
- Teen pregnancy
- Lack of prenatal and pediatric care accessibility

In assessing the three highest issues of concern, many other factors also play a role. Low birth weight and pre-term delivery are pivotal to the determination of infant and neonatal mortality. Early and adequate prenatal care based on gestational age of the neonate are also important determinants of the final birth and death outcome.

Poverty is frequently a common factor and definitely is a major part of a cycle of poor outcomes for teen mothers who usually do not complete their education and, are therefore, unable to break out of poverty and multiple pregnancies.

Teen mothers are usually unmarried and find it difficult to support their family's basic needs. Health care then becomes a low priority for their children.

These issues are further supported by the poor rates which continue in Atlantic City and specifically when examining these rates (infant mortality, teen pregnancy, prenatal care) for the races and when comparing Atlantic City's rates to New Jersey's rates. The disparity in outcomes between African Americans and Whites is startling in Atlantic City but understandable within the context of the fact that of the 25% of Atlantic City residents living below poverty, three-fourths are minorities. **Nevertheless, whether examining the infant mortality rate for the three year average of 1993-1995 or 1994-1996, Atlantic City continues to have the highest infant mortality rate of any city in New Jersey.**

Input from the needs assessments and focus groups identified the additional mitigating factors of: substance abuse, violence/crime, lack of insurance, and lack of provider accessibility and sensitivity.

#### Delivery System:

As with many urban areas, there is a lack of a private provider system. The majority of prenatal and pediatric providers are either part of the hospital delivery system or are supported by government funding which has been dwindling.

Atlantic City was first designated as a federal Health Manpower Shortage Area for primary care in 1979 and that designation was last updated in 1989. Designation as a medically underserved area followed in 1980 and dental

services designation occurred for most of the census tracts in the city in 1994.

In reviewing the availability of the current provider system, none of the prenatal or pediatric providers currently operate any services in the evenings. Saturday hours of operation are minimal and the public clinics operate only during weekdays (including WIC) which makes it difficult for hard-to-reach populations, such as teen mothers and the working poor, to access. In addition, there is almost a complete lack of providers accepting the broad range of Medicaid and offering a sliding fee scale for the indigent who do not qualify for Medicaid. In addition, NJ KidCare was identified as a bureaucracy that is difficult to navigate for most consumers..

When surveying consumers, focus group participants (primarily consumers, and current Healthy Mothers Healthy Babies Coalition members), the following were identified as the top three key issues related to infant mortality, maternal and child health, and teen pregnancy:

- Accessibility of services (hours of operation and service for the uninsured)
- Substance abuse
- Provider sensitivity (language barriers, cultural sensitivity, continuity of care)

In addition, those services needing expansion were identified as:

- Teen parenting services and education
- Primary and dental health services in terms of accessibility (sites and hours of operation)
- Vision care

Providers most often identified the lack of insurance as the primary determinant for whether residents received care at all. And when residents have insurance, it determines where and when they receive care, and the quality of the care and follow up. Comprehensiveness and continuity of care were also outlined as related to the type of insurance.

#### Final Problem Statement

All of the data presented above indicate that Atlantic City is experiencing unacceptably high levels of infant mortality and significant disparities in health care services among racial and economic categories. Additionally, Atlantic City is characterized by other serious problems that are associated with and influence maternal and infant health. Due to continued dwindling resources, State and local governments are unable to provide the financial resources to respond with appropriate public health and welfare programs. As a result, problems of availability and access to health care and social services abound across Atlantic City.

#### Perinatal Health Factors

Whether examining infant mortality rates from 1993 through 1995 or 1994 through 1996, Atlantic City experienced the highest rates of infant mortality, another indicator of access to health services. The infant mortality rate in Atlantic City for this period was 16.2, compared to an infant mortality rate of 7.1 for the entire state of New Jersey during the same period. ***The Atlantic City rate is 2.3 times the State rate and is the highest of any city in New Jersey.*** Within Atlantic City, infant mortality rates

are strongly correlated to race. Between 1994-1996, the rate of infant mortality among African Americans was more than four times higher than the rate among whites; 27.0 and 5.7, respectively. The disparity and rates are worsening based on the three year rolling average process from the initial grant application for planning funds. The infant mortality rate for African Americans in Atlantic City is close to double that of the statewide average for the same years, which were 15.03.

A total of 509 babies were born to teenage mothers less than 18 years of age between 1994 and 1996. This high number points to the need for intensive education and outreach programs that provide teenage women with an awareness of the importance of completing school and practicing sound, consistent methods of birth control. Additionally, as very few teenage women who give birth are married, there is a significant number who remain single mothers, and in effect, poverty stricken. Almost 70% of all women who gave birth in Atlantic City between 1994 and 1996 were unmarried, compared to an unwed mother statewide average of 27.4%.

Low birth weight is the single greatest factor in determining infant survival. Low birth weight, as a consequence of premature birth or impaired fetal growth, can be prevented through early, coordinated comprehensive prenatal care. In Atlantic City between 1994 and 1996, 9.2% of all live births had a low birth weight and 2.0% had a very low birth weight, compared to state low birth weight and very low birth weight averages during the same period of 7.4% and 1.5%, respectively. ***These rates have shown no signs of improvement—in 1997 over 10.7% of infants weighed less than 2500 grams at the time of birth.***

Prenatal care for mothers living in Atlantic City has been significantly lacking compared to state and national standards. The burden of obtaining prenatal and pediatric care generally falls upon women because males and extended family members rarely are seen as responsible for these tasks. In the years 1994-1996, only 53% of pregnant women received prenatal care in their first trimester and 2% of babies born were born to women who had had no prenatal care whatsoever compared to 1.2% for the State as a whole.. Prenatal care has been demonstrated to play a critical role in the prevention of infant illness and mortality.

#### Socioeconomic Factors

Sixty-five percent of the population of Atlantic City is of a minority, or non-white ethnic background. The ethnic origins of the residents that fall into the broad racial categories are extremely diverse, and there is a great deal of cultural and linguistic variety among the city's population. Twenty-three percent of Atlantic City residents over the age of five speak a language other than English, and of this group, almost 25% report that they do not speak English well or they do not speak it at all. This population of non-English speaking people is at an extreme disadvantage in the health care system, as language barriers almost invariably inhibit the flow of communication between patient and provider that is essential for the proper diagnosis, treatment and prevention of disease.

In addition to being affected by the cultural and linguistic differences that inherently disrupt access to health care treatment and information, the residents of Atlantic City are affected economically, as well. While the city is located side by side with the glamour and

extravagance associated with the gaming and casino industry, there is an obvious level of destitution and desperation among many Atlantic City residents. According to data collected by the 1990 census, 25% of Atlantic City's population lives below the poverty level, and of the residents that are living below the poverty level, approximately 77% belong to a minority group.

Per capita income, another indicator of access to health services, is also low in Atlantic City. The overall per capita income in the city is \$12,017. This figure is 64% of the state per capita income of \$18,714 and 83% of the national per capita income of \$14,420. This disparity worsens when broken out by race. Per capita income by racial category is as follows: white (\$16,360), African-American (\$9,942), American Indian, Eskimo, or Aleut (\$2,566), Asian or Pacific Islander (\$12,883) and other (\$6,423). Directly correlated with economic status and equally indicative of an individual's ability to seek out and receive necessary health services is educational attainment. Among the eighteen and older population, 41% percent of individuals did not complete high school, and less than 9% received a bachelors or masters degree.

It has been suggested that all of the above negative socioeconomic factors may directly affect the way a patient is treated by a provider or an office staff member. Discrimination, intimidation and cultural misunderstanding can discourage patients from returning to a provider for check-ups or further treatment and from seeking care elsewhere. Varying cultural influences and preferences may also affect an individual's motivation for seeking care. Religious beliefs may diminish a patient's ability to accept responsibility for their health and their desire to comply

with prescribed care. Cultural sensitivity and awareness should be a priority in communities that serve large populations of minority patients. The complexity of the care system is a result of the lack of coordination between health, social service and community based agencies. Often merely finding a point of entry to begin care is difficult for many patients. This aspect of the service delivery system was highlighted by both the focus groups and in the surveys conducted.

Poor families in need of medical care often have the need for other services such as housing, utilities, nutrition, child care, financial, legal and social counseling. Rarely are these offices located in the same building or locality. This fragmentation of services is further complicated by transportation problems. Mass transit routes do not coincide with the needs of families seeking multiple services, and even when the routes are reasonable, the fares may be too high for them to afford. These issues often lead to either late or no entry to the system for many women and children. As the system of early and adequate preventive health care becomes more complex and difficult for clients to manage, access to care is diminished. Preventive and primary health care is not a high priority among families whose immediate needs are so great. The frequent use of emergency rooms for routine sick care is a reflection of the community's lack of identification with a primary care provider. The poor immunization status of Atlantic City's children reflects health beliefs, competing priorities and a lack of understanding of the needs for preventive care.

### Delivery System Factors

To further exasperate the problems stated above, there is a lack of health care providers within the city. As a result, Atlantic City has been designated a Health Manpower Shortage Area and Health Professional Shortage Area. Atlantic City currently has only one acute care hospital (Atlantic City Medical Center) and very few outpatient clinics. Finding care at locations that accept Medicaid is currently a significant problem for women in the region. Coordination and development of programs and services that are geared towards serving the health needs of the maternal and child population, despite their racial or financial circumstances, needs to be stepped up in order to improve access to care and health outcomes.

As identified by consumers in surveys and focus groups alike, there is a need for expanded service hours of operation to improve accessibility within Atlantic City. Some prenatal, pediatric and WIC evening hours need to be added. In addition, Saturday hours for WIC, immunizations and pediatric clinics need to be examined.

There is a definite need for more education and information relating to prenatal care in Atlantic City. While there is a significant amount of information available to some of the women, it does not seem to be provided consistently. Improved family planning is needed, as six of the eight mothers surveyed had unplanned pregnancies. There is also a delay in women recognizing that they are pregnant, as one mother responded that she did not know until her third trimester. There is also a lack of support for the mothers, as three did not receive any help from the baby's father. Additionally, only two of

the mothers reported that their families were happy about their pregnancy.

There is a lack of immediacy in receiving prenatal care. Two mothers reported that they first scheduled prenatal appointments after two months of being pregnant, and two waited longer than three months. Appointment availability is also a problem in Atlantic City, as half of the mothers had to wait three weeks or longer to receive an appointment. Barriers to receiving prenatal care reported included the inability to find providers that accept Medicaid, lack of insurance, lack of money, and inability to find a babysitter to watch the other children. In addition, many of the scheduled prenatal care visits were missed. Reasons provided by the survey responders included lack of money, illness, the appointments took too long, family problems, and lack of transportation.

Tobacco and drug use also appears to be a significant problem in Atlantic City, as five of the mothers surveyed reported smoking throughout their pregnancy and four mothers reported using street drugs.

#### HEALTHY START CONSORTIUM PROGRESS

The Southern New Jersey Perinatal Cooperative (SNJPC) has overall responsibility for the Atlantic City Healthy Start Project and its successful implementation. SNJPC recognizes that one of the key success factors is the ability to create a successful partnership with community leaders who will play a significant leadership role. Program development, oversight, implementation, and evaluation are among the major responsibilities that will be the charge of community leadership.

The Atlantic City Healthy Mothers/Healthy Babies Coalition (ACHMBC), working along with the Southern New Jersey Perinatal Cooperative, has developed a consortium building process to ensure the successful development of the Atlantic City Healthy Start Coalition. At the core of this development is the true belief in participation as a value. It is important to note here that the use of a participative approach in an environment that does not truly hold it as a value is doomed to failure. Participation does not mean, "rubber stamping" decisions. People are acutely aware if they are being manipulated, so it becomes important to assure a true understanding and orientation to the value in order to facilitate common understanding, trust, and goodwill between coalition members.

The defined outcomes of the consortium building process are:

- Competent community based leadership;
- Broad stakeholder involvement;
- Strategy for sustained broad-based commitment;
- Clear and compelling organizational vision, goals, and objectives.

There are three areas of focus for developing an effective strategy to engage and maintain a broad-based commitment to the goals of the Healthy Start Project.

1. Building Individual Competency and Commitment
2. Building Consortium or Group Competency and Commitment
3. Building Community Competency and Commitment

### *Building Individual Competencies and Commitment*

ACHM/HBC has assumed leadership for the consortium building initiative. Written invitations will be sent to prospective members, followed by personal contact from members of the ACHM/HBC to facilitate dialogue. A presentation packet will be developed for use by ACHM/HBC members, which will assist them in:

- 1) communicating a sense of urgency;
- 2) developing a sense of awareness;
- 3) imparting the comprehensive nature of the Consortium's efforts; and
- 4) focusing their discussions and thinking to achieve support and buy-in. Coalition members who will be making presentations will be coached prior to meeting with prospective Consortium members.

### *Building Consortium Competency and Commitment*

The Consortium's initial work will focus on the development of an organizational vision and strategic plan, goals and objectives. After selecting leadership and defining how the consortium will operate, the consortium will pursue a Future Search Conference. Future Search is a large-system process that will enable the development of a vision and subsequent goals and objectives. One of the most effective ways to build coalitions is to focus the group on a task, assist them in establishing ground rules and opportunities for learning, and allow them to work.

ACHM/HBC leadership is well on its way.

ACHM/HBC and SNJPC have conducted a formal review of the current membership of the Coalition to identify potential members for the Healthy Start Consortium. This review presented opportunities to agree and disagree, to challenge

one another, and to gain clarity. As the Consortium expands from this core group, the behaviors of respectful dialogue, dissent, and finding common ground will continue to be replicated as core values for the organization. Learning these skills through action provides the most effective vehicle.

This process has also provided a forum for developing organization skills. Coalition members need to define roles and relationships, and learn to create and re-create structures that facilitate the accomplishment of common goals.

The following table examines the current relationship that exists between the coalition and other organizations within the community.

COALITION INFORMAL NETWORK	COLLABORATIONS	COALITION MEMBERS
<b>Health Care Providers Atlantic City Medical Providers Atlantic City Schools (K-12) WIC Spanish Community Center Churches Government ARC Business (i.e. McDonald) Volunteer Organization Family Centers Atlantic Human Resources</b>	<b>Atlantic Care Health Systems Atlantic Care Foundation AC Health Care Foundation AC Health Department SJ Perinatal Cooperative Catholic Social Services Family Centers Salvation Army Rescue Mission IHD Texas Avenue School ACHS KidCare Spanish Community Center</b>	<b>AC Health Department Salvation Army Success by Six Family Centers Rescue Mission SJ Perinatal Instate of Human Development Housing Authority Covenant House Project Teach Family Planning March of Dimes HIV Care Consortium AC Board of Education Atlantic County Health Dept Reliance Health Care</b>

### *Building Community Competency and Commitment*

By its very design, a Future Search Conference is intended to generate broad range commitment. People who master the principles are able to implement bolder action plans more quickly than before. Within hours, individuals who have never worked together before are able to build a temporary planning community. The Healthy Start Consortium will assume the leadership role for planning and implementing a Future Search Conference in Atlantic City. This will require the Consortium to gain familiarity with the process; to identify key stakeholders to work with them as a part of the Steering Committee; to provide oversight of Steering Committee activities; to ensure consistency with values of the organization; and to ensure there is a mechanism for evaluating success. Future Search Conferences have been conducted with as few as 30 people and have numbered in the hundreds. After gaining an understanding of the intention of the process, the Steering Committee will decide what is necessary for Atlantic City.

### VI. PUBLICATIONS/PRODUCTS

No publications or products were produced as part of this planning grant.

### VII. DISSEMINATION/UTILIZATION OF RESULTS

Based on the results of the needs assessments, provider surveys, barriers to care surveys and the focus groups, preliminary strategies were identified for evaluation and implementation in the next phase of funding.

## VIII.FUTURE PLANS/FOLLOW-UP

The results and outcomes of this planning grant were used to identify areas of need and to plan strategies for implementation in the next phase of funding.

### Consortium Building:

The first step in the implementation of the Healthy Start grant for the Healthy Start Consortium is to organize and expand the current Healthy Mothers Healthy Babies Coalition. The first task for the Healthy Start Consortium, once formed, will be to prioritize the needs identified in this planning grant as outlined by the survey participants, the focus groups, and based on the health outcomes for Atlantic City.

### Outreach:

The current Healthy Mothers Healthy Babies staff is inadequate to provide the multiple levels of outreach necessary for appropriate and comprehensive assessment and follow up. Pregnant women should be routinely followed, not just those missing a prenatal appointment as current resources dictate. The cadre of outreach workers needs to be enhanced with additional workers. The outreach workers need comprehensive, robust training on the services currently available and not being accessed.

In addition, a multi-pronged public relations and media campaign to promote currently available services and educational opportunities known throughout the Atlantic City community. This education needs to be culturally sensitive, multi-lingual, and promoted by a number of

mediums—radio, TV, newspaper, billboard, etc. Information via providers needs to be consumer oriented. Faith based programs in the Camden Healthy Start project have been extremely successful both with direct provision of services, supporting services such as transportation and with educational programs such as substance abuse education and prevention services. These programs will be further evaluated for implementation in Atlantic City.

Case Management:

High-risk women and children require more intensive follow up beyond routine follow up by an outreach worker. High-risk women will be identified during their pregnancy and followed through postpartum by case manager nurses. All of the sites currently utilize a comprehensive perinatal record. A case management process will be implemented with oversight provided by the Healthy Start Consortium. The perinatal record will serve as the basis for the identification of risk whether medical, environmental, or social, etc.

The implementation phase will include:

1. Definition of the Case Management Team.
2. Specific scoring process to determine high-risk women based on the perinatal record.
3. Description of the home visiting process.
4. Elements of education and prevention services to be offered.
5. Specific management of "hard to reach" women such as pregnant and substance abusing.

Enhanced Clinical Services:

There were multiple issues identified by consumers and the focus groups alike dealing with the provision and delivery of health care services. At a minimum, the following strategies need to be evaluated by the Consortium for implementation in the next phase:

- 1) Expanding the hours of operation to evenings
- 2) Enhancing the provider environments
- 3) Training and education for providers and support staff to improve patient and cultural sensitivity.
- 4) Expansion of currently offered WIC services as an initial point-of-service.
- 5) Initiate direct transportation services.
- 6) Initiate fetal-infant mortality review with providers.

IX. TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE:

Based on the results of the needs assessments, provider surveys, barriers to care surveys and the focus groups, preliminary strategies were identified for evaluation and implementation in the next phase of funding. Once the project has been implemented, the type and amount of support and resources needed to replicate the project will be delineated.

ANNOTATION:

The Atlantic City Healthy Start Project is a coordinated, collaborative effort of health and social service providers, city agencies, community-based organizations, voluntary agencies, community leaders, and consumers. The goal of the Atlantic City Healthy Start Project is to reduce the infant mortality rate, especially in minority populations. Based on the results of the needs assessments, provider surveys, barriers to care surveys and the focus groups, preliminary strategies were identified for evaluation and implementation in the next phase of funding.

KEY WORDS:

Access to Health Care; Adolescent Pregnancy; African-American; Case Management; Child Mortality; Community Based Health Services; Community Development; Community Participation; Consortia; Continuity of Care; Cultural Diversity; Cultural Sensitivity; Data Analysis; Data Collection; Family Centered Health Care; Family Planning; Health Education; Health Promotion; Healthy Mothers/Healthy Babies Coalition; Healthy Start Project; Hispanics; Immunization; Infant Health Care; Infant Morbidity; Infant Mortality; Infant Mortality Review; Infants; Interagency Cooperation; Language Barriers; Low Birthweight; Maternal and Child Health Bureau; Medicaid; Morbidity; Mortality; Needs Assessment; Neonatal Mortality; Neonates; Newborn Screening; Parent Education Programs; Parenting Skills; Peer Counseling; Peer Support Programs; Perinatal Health; Pregnant Adolescents; Pregnant Women; Prematurity; Prenatal Care; Prenatal Diagnosis; Prenatal Screening; Preventive Health Care; Preventive Health Care Education; Provider Participation; Regional Programs; Substance Abusing Mothers; Substance Abusing Pregnant Women; Title V Programs; Uninsured; Urban Population; WIC.

ABSTRACT

PROJECT IDENTIFICATION

Project Title: Atlantic City Healthy Start (HSI  
Infrastructure/Capacity Building)

Project Number: H50MC00003-01

Project Director: Judy Donlen, DNSc, JD, MSN

Grantee Organization: Southern New Jersey Perinatal  
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Project Period: 7/1/99 - 6/30/00

Total Amount of Grant Awarded: \$150,000

I. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS: The purpose of the Atlantic City Healthy Start Project is to reduce the infant mortality rate in Atlantic City, especially in minority populations. The Atlantic City maternal and child health population is at an extreme disadvantage in receiving the care that is necessary for improving the health outcomes and quality of life of the community. The grantee organization, Southern New Jersey Perinatal Cooperative (SNJPC), is one of seven regional maternal and child health consortia. SNJPC's status as a licensed MCHC and recipient of NJDHSS administered grant funds helps assure the success of the Atlantic City Healthy Start Project because of the collaborative relationships SNJPC maintains with the New Jersey Department of Health and Senior Services and other state agencies, such as the Departments of Human Services, Education and Community Affairs. SNJPC has been active in Atlantic City for over a decade, providing staff support to collaborative efforts such as the Healthy Mothers Healthy Babies Coalition and securing funding for numerous new services through Title V funding, foundations and other sources. The SNJPC and the Atlantic City Healthy Mothers Healthy Babies Coalition (the Project Area Consortium) are

integrally involved with programs aimed at improving the health status of women and children in the project area and statewide.

## II. GOALS AND OBJECTIVES:

The overall goal of the Atlantic City Healthy Start Project is to reduce the infant mortality rate, especially in the minority populations. The objective of the first phase of the Atlantic City Healthy Start Project was to conduct a full needs assessment to identify gaps and disparities in Atlantic City's delivery system. Upon completion of the full needs assessment, Atlantic City Healthy Mothers Healthy Babies Coalition (ACHMHBC) initiated a second phase to expand the current coalition to include all stakeholders in Atlantic City. A team, the Atlantic City Healthy Start Consortium, will be built to identify models and strategies that can be implemented to address the identified needs.

III. METHODOLOGY: The first phase of the project, the full needs assessment, consisted of data collection efforts that were focused on the provider and patient population. A variety of formats were used in the data collection: vital statistics, utilization and service reception data, statistical small area health analysis, local area provider assessments, target surveys and focus groups. The second phase of the project addressed the problems illustrated by the full needs assessment through identification of effective health care delivery models and the development of comprehensive community initiatives through 1) formation of an expanded Healthy Start Consortium of health care providers, social services agencies, schools and local government; and 2) evaluation of health care delivery strategies designed to meet the health needs of the maternal and child population. Strategies that were evaluated and benchmarked for future implementation include case management and care coordination, home visiting programs, and current outreach projects.

IV. EVALUATION: The Southern New Jersey Perinatal Cooperative conducted the necessary data collection and evaluation of the Atlantic City Healthy Start project. SNJPC has a perinatal database for the collection and analysis of data. Electronic birth certificates are used to increase the timeliness and accuracy of the state's birth information. SNJPC also provides specially trained staff to assist hospitals in the implementation and use of the Neonatal

Information System, a computer program designed to track the course of an infant's treatment and outcome.

The evaluation involved an ongoing assessment of progress made in the planning process as well as final recommendations for strategies to be implemented. The primary objectives of the process assessment were to describe the interventions pursued by the various grantees, identify gaps and any subsequent problems encountered in integrating service coordination. The evaluation also assessed the coalition's ability to implement partnership relationships. During the planning period, a database was created to aid in the collection of information on participant data and services planned to be implemented. The process evaluation will continue throughout the duration of the grant.

V. RESULTS/OUTCOMES (POSITIVE & NEGATIVE): The following progress has been made during the planning phase of the Healthy Start project for Atlantic City:

1. A database of all stakeholders both consumers and providers has been developed. This was further enhanced by adding those interested consumers who were focus group participants.
2. Timelines to track the development of the Healthy Start Consortium have been established with the key members of the current Healthy Mothers Healthy Babies Coalition.
3. A data subcommittee of the Healthy Start Consortium was established to oversee the implementation of tracking the health outcomes data, specifically as a fetal-infant mortality review process utilizing the "periods of risk" model to perform causal analysis.
4. A plan to organize the Healthy Start Consortium, identify the target population, outline the needs and track the interventions by assigned agency was developed.
5. An evaluation subcommittee was formed to oversee the project and track the progress towards all established goals.
6. The database was enhanced by the addition of key elements not currently cohorted for city residents by race/ethnicity. This data became available from the Center for Health Statistics of the New Jersey State Department of Health and Senior Services.
7. The Southern New Jersey Perinatal Cooperative is currently the manager of the Service Bureau for the New Jersey Immunization Information System in the city

of Camden (Immunization Registry). The Southern New Jersey Perinatal Cooperative has implemented this service in Atlantic City in order to coordinate immunizations given in all private and public pediatric and family practice locations.

VI. PUBLICATIONS/PRODUCTS: No publications or products were produced as part of this planning grant.

VII. DISSEMINATION/UTILIZATION OF RESULTS: Based on the results of the needs assessments, provider surveys, barriers to care surveys and the focus groups, preliminary strategies were identified for evaluation and implementation in the next phase of funding.

VIII. FUTURE PLANS/FOLLOW-UP: The results and outcomes of this planning grant were used to identify areas of need and to plan strategies for implementation in the next phase of funding.

IX. TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE: Based on the results of the needs assessments, provider surveys, barriers to care surveys and the focus groups, preliminary strategies were identified for evaluation and implementation in the next phase of funding. Once the project has been implemented, the type and amount of support and resources needed to replicate the project will be delineated.