

Contract No.: 240-93-0050
MPR Reference No.: 8166-113

Reducing Infant Mortality

Lessons Learned from Healthy Start

Final Report

July 2000

*Barbara Devaney
Embry Howell
Marie McCormick
Lorenzo Moreno*

Submitted to:

DHHS/HRSA/OPEL
Parklawn Building, Room 14-36
5600 Fishers Lane
Rockville, MD 20857

Project Officer:

Karen Thiel Raykovich, Ph.D.

Submitted by:

Mathematica Policy Research, Inc.
P.O. Box 2393
Princeton, NJ 08543-2393
(609) 799-3535

Project Director:

Embry Howell

ACKNOWLEDGMENTS

This report represents a team effort in which many individuals made key contributions. The authors gratefully acknowledge the assistance of Dexter Chu, Melissa Seeley, Miki Satake, David Edson, and Mary Harrington of the Research Division of Mathematica Policy Research; Susan Sprachman, Rhoda Cohen, Cheryl DeSaw, and Frank Potter of the Survey Division of Mathematica Policy Research; Barbara Foot and Liz Closter (^), formerly of Mathematica Policy Research; Lisa Deal of the David and Lucile Packard Foundation; Doug Richardson of the Harvard School of Public Health; Paul Wise of Boston University; Ian Hill, Beth Zimmerman, and Renee Schwalberg of Health Systems Research, Inc.; and Luke Henderson and Marilyn Robinson of Riva Market Research for their assistance conducting and transcribing focus groups.

The authors recognize and appreciate the substantial assistance and encouragement provided by Dr. Karen Thiel Raykovich of the Office of Planning, Evaluation, and Legislation/Health Resources and Services Administration (HRSA); the review and comments provided by Dr. Peter van Dyck, Kerry Nesseler, Paul Nannis, Doris Barnette, and Dr. Earl Fox of HRSA; and the assistance of the Division of Perinatal and Women's Health (formerly the Division of Healthy Start) at HRSA and the Technical Advisory Group for the evaluation. The authors especially thank each of the following Healthy Start programs S including program staff, consortium members, providers, and program clients:

- # Baltimore Healthy Start Program
- # Birmingham Healthy Start Initiative
- # Boston Healthy Start Initiative
- # Chicago Healthy Start Project
- # Cleveland Healthy Family/Healthy Start Project
- # Detroit Healthy Start Initiative
- # District of Columbia Healthy Start
- # New Orleans Healthy Start/Great Expectations
- # Healthy Start/New York City
- # Northern Plains Healthy Start
- # Northwest Indiana Healthy Start
- # Oakland Healthy Start
- # United Way of South Carolina S A Rural Community Partnership (Pee Dee)
- # Philadelphia Healthy Start Initiative
- # Allegheny County/City of Pittsburgh Healthy Start Program

The authors also thank Jane Nelson and Roy Grisham of Mathematica Policy Research for producing this report.

CONTENTS

EXECUTIVE SUMMARY	xi
Chapter I: INTRODUCTION	1
Chapter II: THE HEALTHY START PROGRAM	9
Chapter III: COMMUNITY INVOLVEMENT IN THE HEALTHY START PROGRAMS	25
Chapter IV: THE HEALTHY START TARGET POPULATION AND PROGRAM CLIENTS	29
Chapter V: EFFECTS OF HEALTHY START ON PRENATAL CARE, INFANT MORTALITY, AND BIRTH OUTCOMES	37
Chapter VI: CONCLUSIONS AND LESSONS LEARNED	57
REFERENCES	65
APPENDIX A	67

TABLES

Table		Page
1	CHARACTERISTICS OF THE HEALTHY START PROJECT AREAS	5
2	CASE MANAGEMENT SERVICES RECEIVED BY HEALTHY START CLIENTS	13
3	ENHANCEMENT TO CLINICAL SERVICES FUNDED BY HEALTHY START	17
4	HEALTHY START SERVICE PROVIDER NETWORK	19
5	HEALTHY START GRANT AWARDS	22
6	HEALTHY START CONSORTIA	26
7	HEALTHY START COMMUNITY EMPOWERMENT	28
8	AN OVERVIEW OF THE HEALTHY START TARGET POPULATION: MOTHERS OF INFANTS BORN IN 1996	31
9	ENROLLMENT OF TARGET POPULATION IN HEALTHY START, 1995	32
10	NUMBER OF HEALTHY START MATERNAL AND INFANT CLIENTS BY PROJECT AREAS S FISCAL YEAR 1996	33
11	CHARACTERISTICS OF HEALTHY START CLIENTS AND NONPARTICIPANTS	34
12	PERCEIVED QUALITY OF PRENATAL CARE	45
13	EFFECTS OF HEALTHY START ON PRETERM, LOW, AND VERY LOW BIRTHWEIGHT RATES, 1996	49
14	SUMMARY OF OUTCOMES ANALYSIS RESULTS	51

FIGURES

Figure		Page
1	CONCEPTUAL MODEL OF THE EFFECTS OF HEALTHY START	6
2	UTILIZATION OF PRENATAL CASE MANAGEMENT SERVICES	12
3	UTILIZATION OF HEALTHY START SUPPORT SERVICES	14
4	HEALTHY START EXPENDITURES BY EXPENDITURE CATEGORY FISCAL YEAR 1996	23
5	EFFECTS OF HEALTHY START ON THE ADEQUACY OF PRENATAL CARE UTILIZATION	40
6	EFFECTS OF HEALTHY START ON THE ADEQUACY OF PRENATAL CARE INITIATION	41
7	EFFECTS OF HEALTHY START ON THE ADEQUACY OF PRENATAL CARE VISITS	42
8	CONTENT OF PRENATAL CARE	43
9	EFFECTS OF HEALTHY START ON SATISFACTION WITH CARE	44
10	INFANT MORTALITY RATES, HEALTHY START PROJECT AREAS AND COMPARISON AREAS	46
11	EFFECTS OF HEALTHY START ON INFANT MORTALITY	47
12	LOW BIRTHWEIGHT RATE, VERY LOW BIRTHWEIGHT RATE, AND PRETERM BIRTHWEIGHT RATE	48

EXECUTIVE SUMMARY

In response to concern over high infant death rates, the Healthy Start program was launched in 1991 by the Health Resources and Services Administration (HRSA) of the U.S. Public Health Service to reduce infant mortality by 50 percent and to improve maternal and infant health in communities with high infant death rates.

Healthy Start is a community-based initiative in which local programs designed and implemented interventions targeting women, infants, their families, and the communities where they live. These interventions included outreach and case management for pregnant women and infants; broad-based public information campaigns; support services; individual and classroom-based health education; co-location of prenatal care services; and enhanced clinical services for women and infants.

In fall 1991, HRSA initially chose 13 urban areas and 2 rural areas in which to implement the five-year Healthy Start demonstration. The original 15 project areas were Baltimore, Birmingham, Boston, Chicago, Cleveland, Detroit, the District of Columbia, New Orleans, New York City, Northern Plains, Northwest Indiana, Oakland, the Pee Dee region of South Carolina, Philadelphia, and Pittsburgh.

Total funding for the original 15 Healthy Start project areas through the five-year demonstration period was \$345.5 million. Congress subsequently appropriated \$96 million to continue the existing Healthy Start programs for a sixth year, one year beyond the original five-year time frame. Subsequent budget appropriations funded additional project areas, as well as the 15 original project areas, although at reduced levels. The fiscal year 2000 budget includes \$90 million in funding for 94 Healthy Start programs.

PROGRAM ADMINISTRATION

To implement the program interventions, Healthy Start grantees developed a variety of administrative arrangements. Most of the grantees (11) were city, county, or state health departments. Using a health department for administration had several benefits:

- # Health departments all had qualified staff to oversee program development.
- # Health departments were linked to a jurisdiction's political and health care leadership, which encouraged the support and involvement of leaders.

- # Health departments could help to sustain important program components when federal funding declined.

On the other hand, given civil service procedures, health departments also had the disadvantage of slowing hiring and contracting for services. Additionally, some health departments had a poor relationship with the providers and residents of the communities they served, which resulted in a distrust of the Healthy Start program.

To address these potential problems, four of the health department grantees relied on private, nonprofit organizations to implement and monitor the Healthy Start program, and four additional Healthy Start grantees were themselves existing nonprofit organizations.

HEALTHY START PROGRAM INTERVENTIONS

Given a set of broad goals, a mandate for community involvement, and some guiding principles, Healthy Start programs had flexibility in designing and implementing their programs. The result was a set of 15 individual Healthy Start demonstration programs, each reflecting the circumstances and resources available in its community. The Healthy Start programs included both service delivery and system change components.

The service delivery component of Healthy Start fell into three categories: (1) outreach and case management programs designed to identify and enroll women and infants in the program and to remain in contact with them throughout pregnancy and the child's infancy; (2) a network of support services including, for example, health education, transportation, child care, employment assistance, and mental health and substance abuse counseling; and (3) enhancements to available clinical services. The system change components of Healthy Start included consortium development, management information systems, public information campaigns, and infant mortality review.

Service Delivery in Healthy Start

Direct service delivery accounted for approximately two-thirds of Healthy Start expenditures. Most of these services were provided to a defined set of clients, but some services such as outreach and health education were provided to larger community groups that could not be easily counted or identified. In fiscal year 1996, Healthy Start served 49,695 mothers and infants. The variation across program areas in the number of clients served annually is large from more than 7,000 in Cleveland and Philadelphia to under 1,000 in Pee Dee.

Three main service delivery components of Healthy Start were:

- # *Case Management.* All programs implemented some kind of case management program, with the overall objective of ensuring that low-income women and their families have access to and receive the services they need during pregnancy and infancy. Four core functions of Healthy Start case management were: (1) initial

contact or outreach; (2) intake; (3) assessment, care planning, and referrals; and (4) ongoing contact and tracking. While all Healthy Start programs employed a mix of lay and professional case management staff, several programs relied heavily on lay community workers as their primary case managers. These programs increased the employment of community residents, thus investing in the community and facilitating community buy-in and support for Healthy Start.

- # *Support Services.* Healthy Start provided a wide range of support services. The most common support services were transportation assistance, substance abuse treatment and counseling, health education, and child care.
- # *Enhancements to Clinical Services.* All Healthy Start programs funded a wide range of clinical services to pregnant women and their families. Across 14 of the 15 project areas, over 167 clinical providers received funding to enhance existing clinical services. Programs used these funds in a variety of ways to hire additional staff or increase salaries, to eliminate waiting time, to provide health education, and to add child care or play areas to clinic sites.

System Change Interventions in Healthy Start

From its inception, the Healthy Start program emphasized improving systems of care in communities serving low-income, high-risk women and their families. As a result, many components of Healthy Start went beyond providing direct services and included the following efforts:

- # *Developing and Sustaining Central Program Consortia.* All Healthy Start grantees were required to establish consortia of community leaders, community residents, medical and social service providers, and community organizations to plan and implement program services.
- # *Service Integration and Coordination.* Healthy Start operated within a large network of providers. Healthy Start had three main strategies for coordinating with this network: (1) formal and informal referral arrangements through the case management process; (2) co-location of services; and (3) improved data linkages.
- # *Public Information.* The public information efforts of Healthy Start were among the most innovative and interesting of program activities, and included campaigns using hotlines, national television, radio, posters, and billboards.
- # *Management Information Systems.* These systems were expected to facilitate internal program management and meet federal reporting requirements on clients served and services received. Most programs struggled to develop a management information system that met HRSA requirements.
- # *Infant Mortality Review.* Infant mortality review programs were designed to help programs identify the factors involved in the infant deaths in their communities. The reviews examined infant deaths to determine the clinical, social, and health

factors associated with infant death, and to make recommendations to improve infant outcomes in the community.

HEALTHY START IMPLEMENTATION

The following are some of the key findings regarding the implementation of Healthy Start:

- # It is feasible to implement a community-based initiative, but Healthy Start implementation took longer than expected.
- # Healthy Start was successful at enrolling women with high risk of adverse pregnancy outcomes.
 - Healthy Start clients were more likely than other women living in the project areas to be under age 20, to be African American, to have less than high school education, to have lower income, and to be unmarried.
 - Healthy Start clients were less likely than other women to receive prenatal care in a private office and were more likely to have an unintended pregnancy.
- # Overall, the Healthy Start programs were successful in establishing case management programs.
 - Healthy Start demonstrated that including lay workers as members of case management teams was feasible and helped identify high-risk women and enroll them in case management programs. The programs felt that the “inside” link of community lay workers was important for identifying pregnant women, enrolling them in Healthy Start, and designing and targeting services.
 - Healthy Start clients were more than three times as likely as nonparticipants to receive case management services during pregnancy.
 - Referrals were an important component of Healthy Start case management, but tracking service receipt was very difficult. Perhaps reflecting the high-risk nature of clients, Healthy Start case management programs experienced problems in maintaining contact with clients.
 - Case management staff provided important social support to pregnant and parenting women.
- # Healthy Start had a strong emphasis on community involvement in planning and implementing the program. With varying intensity and success, all programs encouraged community involvement. Community involvement was, however, a time-consuming and labor-intensive process. Involving community residents was particularly difficult; job creation appeared to be the best way to involve lay residents.

HEALTHY START OUTCOMES

The national evaluation of Healthy Start examined whether the demonstration programs affected a broad range of outcomes, including prenatal care utilization, preterm birth rate, low- and very-low birthweight rates, and the infant mortality rate. The principal results are the following:

- # *Prenatal Care Utilization.* Healthy Start was associated with significant improvements in measures of prenatal care utilization.
 - In 8 of the 15 project areas, Healthy Start was associated with improved adequacy of prenatal care utilization: Baltimore, Birmingham, Chicago, New Orleans, New York City, Northern Plains, Oakland, and Philadelphia.
 - Healthy Start was associated with increases in the adequacy of prenatal care initiation in 4 of the 15 project areas: Birmingham, New Orleans, New York City, and Philadelphia.
 - Healthy Start was associated with improved adequacy of the number of prenatal care visits in 9 of the 15 project areas: Baltimore, Birmingham, Boston, Chicago, New Orleans, New York City, Northern Plains, Oakland, and Philadelphia.
- # *Preterm Birth Rate.* In 4 project areas, Healthy Start was associated with a lower preterm birth rate: Birmingham, New Orleans, Oakland, and Philadelphia.
- # *Low and Very Low Birthweight Rates.* Three project areas **S** Birmingham, Detroit, and the District of Columbia **S** had significant reductions in the rate of low birthweight resulting from Healthy Start. In Birmingham, Boston, and Pittsburgh, Healthy Start was related to reductions in the rate of very low birthweight.
- # *Infant Mortality Rate.* Infant mortality rates declined significantly in the Healthy Start project areas between the baseline period of 1984 through 1988 and 1996. Infant mortality rates declined by roughly the same magnitude in matched comparison areas and in the nation as a whole. In two project areas, New Orleans and Pittsburgh, Healthy Start was associated with significant reductions in infant mortality.

Two project areas **S** New Orleans and Pittsburgh **S** had significant improvements in several birth outcomes and large, statistically significant reductions in infant mortality attributed to Healthy Start. Three additional project areas **S** Baltimore, Birmingham, and Oakland **S** also had significant improvements in birth outcomes and reductions in infant mortality that were large and close to statistical significance. Philadelphia Healthy Start had significant improvements in all measures of prenatal care utilization and a significant reduction in the preterm birth rate.

LESSONS LEARNED

After looking carefully at the findings from both the implementation analysis and outcomes analysis, several conclusions emerge about factors influencing the implementation and effects of Healthy Start:

- # *Healthy Start programs filled important gaps in services.* The services provided by Healthy Start outreach, case management, and support services are generally not provided in traditional clinic settings and filled a gap in the service delivery network for low-income women and children.

- # *Strong program organization and administration, with stable program leadership, is associated with better program implementation and improved outcomes.* Four of the six more successful programs with the most positive outcomes were ranked highly on program organization and administration.
 - An efficient administrative structure for administering Healthy Start was a combination of public and private, nonprofit administration. Three of the more successful programs relied on a private, nonprofit agency to implement and manage the program.

 - Timely hiring of strong senior staff and stability of program staff also contributed to successful implementation. Four of the six programs with the most positive outcomes had strong program directors during the demonstration period.

- # *Programs that focused on service coordination, with close links to the existing clinical care system, appeared to be more successful than others.* A major focus of Healthy Start was to link women and their families to needed services. Healthy Start program staff believed that coordinating and enhancing existing services was more important than creating new services. All of the more successful programs ranked very highly on service coordination.

- # *Strong consortia were not necessary for program success.* Programs with very active consortia devoted considerable energy and staff time to convening and managing the consortia. While two of the Healthy Start programs that ranked highly on consortium development showed improved birth outcomes, a strong consortium did not appear necessary for improved outcomes. Other programs also had strong consortia but did not have improved outcomes, and two Healthy Start programs with the most improved outcomes were ranked low on consortium development.

- # *Community involvement through the employment of community residents was associated with improved outcomes in some but not all programs.* Employing residents of Healthy Start communities to deliver services was a common strategy to facilitate community involvement in many Healthy Start programs. Four project areas with the most improved birth outcomes implemented

programs based on significant employment of community residents. So also did other Healthy Start programs, without the associated improvements in infant mortality and related birth outcomes.

Community-based intervention such as Healthy Start may have longer-term impacts that have not been measured. Because of the mandate for community involvement, Healthy Start implementation took longer than expected. Many of the interventions implemented were focused on linking women with available services, thereby promoting a longer-run attachment to both the health care and the social support systems. Such long-run attachment may affect the future health and well-being of women and their families. In addition, the community activities and linkages fostered by community involvement may have positive long-term consequences in the Healthy Start project areas that have not been measured in this evaluation.

CHAPTER I

INTRODUCTION

Infant death is a tragedy for both families and communities. Fortunately, most infants **S** more than 99 percent of them **S** survive their first year of life. Nonetheless, with a rate of 7.1 infant deaths per 1,000 live births in 1997, the United States continues to have higher rates of infant mortality than most other industrialized countries, ranking 25th in the world (Ventura et al. 1998a; National Center for Health Statistics 1998). In addition, significant disparities in infant mortality are found across communities and racial and ethnic subgroups.

In response to concerns over high infant mortality rates, the Healthy Start program was launched in 1991 by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services to demonstrate approaches to reduce infant mortality by 50 percent over five years and to improve maternal and infant health in communities with high infant mortality rates. HRSA initially awarded grants to 13 urban areas and 2 rural areas to implement a five-year Healthy Start demonstration.

Healthy Start is a community-based initiative in which local programs designed and implemented interventions targeting women, infants, their families, and the communities where they live. These interventions included outreach and case management for pregnant women and infants; broad-based public information campaigns; social support services; individual and classroom-based health education; co-location of services; and enhanced clinical services.

The national evaluation of Healthy Start includes a detailed process and outcomes analysis. The process analysis focuses on describing and documenting the Healthy Start program **S** the community context, interventions, and implementation. The outcomes analysis assesses whether Healthy Start achieved its goals of reducing infant mortality and improving maternal and infant health. The time period covered by the national evaluation is the five-year demonstration period, fiscal years 1992 through 1996.

This report synthesizes the results of a cross-cutting, national evaluation of the original 15 Healthy Start project areas: Baltimore, Birmingham, Boston, Chicago, Cleveland, Detroit, the District of Columbia, New Orleans, New York City, Northern Plains, Northwest Indiana, Oakland, the Pee Dee region in South Carolina, Philadelphia, and Pittsburgh.

The discussion below first describes the Healthy Start demonstration and the 15 original Healthy Start project areas. The following chapter focuses on the implementation of Healthy Start, with particular emphasis on the key interventions of outreach and case management, health education, and support services. Chapter III discusses community involvement in Healthy Start and Chapter IV describes the Healthy Start target population and program clients. Chapter V presents findings on the effects of Healthy Start on prenatal care utilization, infant mortality, and other birth outcomes. Lessons learned are the focus of the final chapter, which summarizes both the evaluation findings and their implications. Appendix A presents a summary of the major reports produced by the national evaluation.

LAYING THE GROUNDWORK: GUIDING PRINCIPLES AND SITE SELECTION

Healthy Start evolved out of a White House report written in the late 1980s in response to concerns over high levels of infant mortality. The rate of decline in the nation's infant mortality rate had slowed, and, relative to other developed countries, the U.S. ranking had fallen. In addition, there were significant racial disparities in infant mortality rates: black infants in the late 1980s were more than twice as likely as white infants to die in their first year of life. The result was a recommendation to fund a major program in selected communities in order to demonstrate effective approaches for reducing infant mortality. Such an approach should mobilize and coordinate the resources available in local communities to provide parents with both the means and the strengthened sense of personal responsibility to care for their infants (Howell et al. 1998).

Designed initially as a demonstration program, Healthy Start was this new approach. The Healthy Start demonstration sought to demonstrate whether communities with high rates of infant mortality could **S** with substantial planning and community involvement **S** develop programs that both reduce infant mortality and address the social and health care needs of communities. HRSA issued *Guidance for the Healthy Start Program* in May 1991. This document described the framework for the program.

“The sites will utilize a community-based, family-centered, and culturally competent approach that will strengthen the maternal and infant care system and bring childbearing-aged women, pregnant women, and infants into care early, maintain them in care, and assist families in changing their community and home environments to be more conducive to a healthy start for infants.”

The guiding principles of Healthy Start were innovation, community commitment and involvement, increased access, service integration, and personal responsibility (Division of Healthy Start 1994). *Innovative approaches* were promoted to address persistent factors contributing to infant mortality and to meet the challenge of linking women and infants to available services. Extensive *community commitment and involvement* were thought to be critical to the success of the initiative. *Increased access and service integration* would ensure that a coordinated service package is available to women and infants. Finally, *personal responsibility* for individual and family health was considered essential for adopting an appropriate primary health care regimen

and eliminating risk behaviors associated with infant mortality S substance abuse, tobacco use, poor nutrition, unintended pregnancies, and exposure to sexually transmitted diseases.

To be eligible, a project area had to have an average annual infant mortality rate of at least 15.7 deaths per 1,000 live births during the five-year period 1984-88, a rate that was 50 percent higher than the national average during that time. Project areas also had to have at least 50, but no more than 200, infant deaths per year. The initial demonstration period was five years, with the first year devoted to developing a comprehensive plan. Forty proposals from around the country were submitted, and 21 were approved for funding. In September 1991, 15 communities were selected to receive planning grants.

To give communities the flexibility to build on local resources and address local issues, HRSA set broad goals and criteria for the Healthy Start grantees, yet allowing them the flexibility to design their own approach. All Healthy Start grantees were required to develop a Comprehensive Healthy Start Plan that would accomplish the following objectives:

- # *Focus on Reducing Infant Mortality.* The overarching goal of Healthy Start was to reduce infant mortality by 50 percent over five years.
- # *Include the Community in Planning.* All Healthy Start grantees were required to establish consortia of community leaders, community residents, medical and social service providers, and community organizations to plan and implement program services.
- # *Assess Local Needs.* Grantees were to conduct a needs assessment to identify a core set of community problems and the resources available to address them.
- # *Develop a Package of Health and Social Services for Pregnant Women and Infants.* Based on the needs assessment, each grantee determined the spectrum of services to be offered.
- # *Develop a Service System Plan.* Grantees were required to develop and implement a service system plan that would identify those systemic issues that contribute to high rates of infant mortality and develop strategies to address these issues. The service system plan was expected to include the following:
 - Strategies to improve awareness of what services exist
 - Efforts to identify the multiple ways that clients enter the system and implementation of a common set of procedures to make intake more efficient and less burdensome (e.g., simplify the eligibility determination process)
 - Mechanisms for ensuring that multiple funding streams result in adequate and timely payment of services

- Improvements in how services are provided to women and their families, such as eliminating waiting lists and minimizing waiting times
 - Treatment plans, with appropriate referrals and followup, that involve and coordinate the multiple providers in the community
 - Management information systems that track individual service receipt and facilitate appointment management, patient flow, referral and followup, multi-agency treatment plans, and service coordination
 - Infant mortality review processes to analyze medical, socioeconomic, and community factors contributing to infant mortality and to communicate findings from these reviews to the consortium for use in program planning
- # *Increase Public Awareness.* Grantees were required to develop a public information and education component that would focus on (1) providing community residents with information on the goals of Healthy Start and the availability and location of services, and (2) sensitizing the larger community to issues relating to infant mortality.
- # *Evaluate the Initiative.* Grantees were to monitor their progress toward their goals and cooperate with a national evaluation. Additional local evaluation activities could complement the national evaluation, at the grantee's option.

THE HEALTHY START PROJECT AREAS

The 15 original Healthy Start project areas were a combination of inner-city communities, clusters of cities, and rural areas. Twelve of the project areas were inner-city communities. Northwest Indiana was a cluster of four smaller cities within Lake County, Indiana (East Chicago, Gary, Hammond, and Lake Station). Pee Dee included six rural counties in South Carolina S Chesterfield, Darlington, Dillon, Marion, Marlboro, and Williamsburg. The Northern Plains project area encompassed 19 American Indian tribal organizations in Iowa, Nebraska, North Dakota, and South Dakota.

The project areas differed greatly from one another in terms of their geographic, cultural, and political environment (see Table 1). Although the 1984 to 1988 period was used as the baseline period for calculating a project area's infant mortality rate, Table 1 focuses on the three-year period just prior to Healthy Start (1989 to 1991). During this three-year period, the project areas had an average of approximately 76,000 births per year. The infant mortality rate ranged from 10.7 in the Boston project area to 24.9 in Detroit project area. The national rate was 9.3 during that same time period. With the exception of Northern Plains, the rates of low birthweight also were considerably higher than the U.S. average (7.0 percent).

All project areas had a high proportion of the population in poverty and a high proportion of minority residents. Except for Northern Plains, all had a relatively large proportion of births that were African American, and five project areas had significant proportions that were Hispanic (Boston, Chicago, New York City, Northwest Indiana, and Oakland).

Table 1: Characteristics of the Healthy Start Project Areas

Project Area	Births, 1989-1991					Percentage of Population <Poverty, 1989
	Total	Infant Mortality Rate	Percentage Low Birthweight	Percentage African American	Percentage Hispanic	
Baltimore	3,684	15.9	18.1	96.9	0.3	41.6
Birmingham	10,295	19.6	12.8	88.3	0.1	30.2
Boston	18,652	10.7	10.0	52.5	20.1	22.9
Chicago	19,093	19.8	14.0	62.5	26.0	46.4
Cleveland	16,460	17.2	15.0	90.6	1.8	34.4
Detroit	32,430	24.9	16.7	94.6	NA	39.8
District of Columbia	7,633	22.5	16.9	94.5	0.8	24.0
New Orleans	12,272	17.4	15.1	95.0	0.8	48.7
New York	33,670	18.5	14.5	68.7	26.1	36.0
Northern Plains	8,222	17.5	5.7	0.0 ^a	0.0	49.6
Northwest Indiana	13,289	12.0	10.0	50.9	14.6	21.4
Oakland	13,863	12.4	10.7	52.6	23.4	26.3
Pee Dee, SC	11,535	15.8	10.8	57.3	0.5	24.4
Philadelphia	16,960	15.2	14.4	82.1	1.0	24.0
Pittsburgh	11,950	17.4	12.5	62.8	0.5	26.9
United States	12,310,077	9.3	7.0	16.0	14.5	13.1

SOURCE: State vital statistics birth and death files, 1989-1991; percent < poverty is from the 1990 census.

NA = not available.

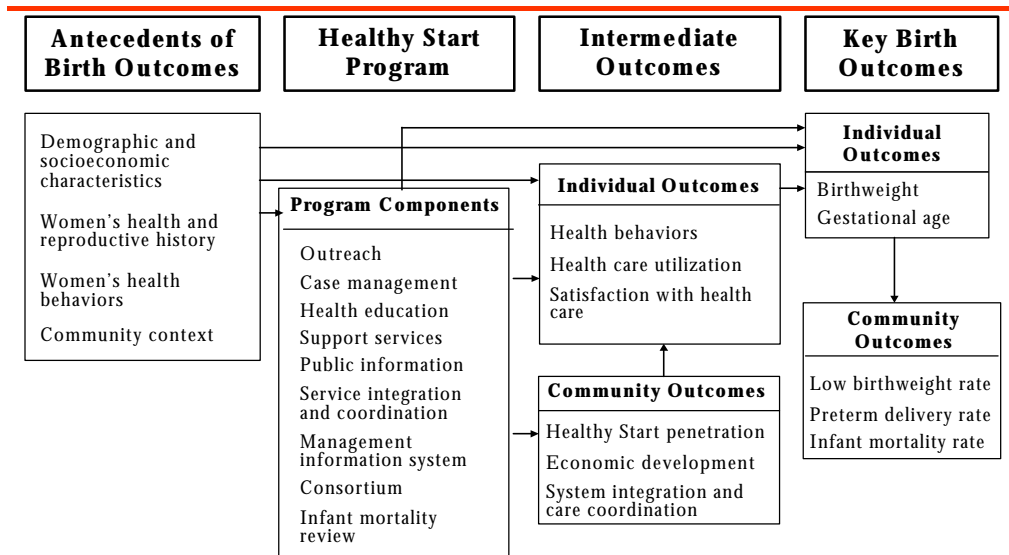
^a Northern Plains is 100 percent American Indian.

Although not shown in the table, the Healthy Start project areas experienced a variety of problems such as high unemployment rates, community and domestic violence, substance abuse, substandard housing, homelessness, and public health problems. Infant mortality was only one part of a complex constellation of social and health problems.

CONCEPTUAL MODEL OF THE HEALTHY START PROGRAM

Based on the HRSA Guidance and published background material on Healthy Start (Lewin-ICF and MDS Associates 1992), the national evaluation developed a conceptual model (see Figure 1). This model highlights the important linkages between the antecedents of key birth outcomes; the Healthy Start program interventions; intermediate outcomes relating to health care utilization, health behaviors, and community changes; and resulting changes in both individual and community birth outcomes, including the ultimate program goal of reducing infant mortality.

Figure 1
Conceptual Model of the Effects of Healthy Start



The antecedents of key birth outcomes are primarily the background characteristics of the women and their families. Any of the background factors may have an important, direct effect on the long-term outcomes, or they may operate indirectly by influencing either program participation or intermediate outcomes. For example, independent of any programs available, these background factors may have strong influences on health behaviors and health care utilization, which, in turn, may affect birth outcomes and infant mortality. Antecedent factors also influence whether women and their infants enroll in Healthy Start.

Through its broad range of program interventions, Healthy Start attempts to influence the behaviors and outcomes of women and their families in multiple ways. As discussed in greater detail in the following chapter, the Healthy Start interventions include outreach and case management, health education, a range of support services, public information campaigns, service integration and coordination, a management information system, consortium development, and infant mortality reviews.

Participation in Healthy Start may influence key birth outcomes, both directly and indirectly through intermediate changes in individual behavior and community outcomes. For example, if the Healthy Start public information campaign is successful at improving awareness of the causes of infant mortality, then it may have direct impacts on individual birth outcomes. Or, if Healthy Start leads to increased care coordination (community outcome) and links women to available services, then use of early and appropriate health care may increase, leading to improvements in birth outcomes.

This conceptual framework suggests several issues and research questions for the evaluation of Healthy Start.

- # What were the Healthy Start program interventions, and how were they implemented in the 15 original project areas? Specifically, the evaluation addressed the following issues:
 - Program interventions designed and implemented in the project areas
 - Community context for the local Healthy Start programs and characteristics of the population at risk
 - Community coalitions and networks formed
 - Who was served by Healthy Start and services received
 - Facilitators and barriers to program implementation
- # What were the effects of Healthy Start on intermediate individual and community outcomes?
 - Prenatal care utilization
 - Content of and satisfaction with care
 - System integration and care coordination
- # What were the effects of Healthy Start on infant mortality, rates of low and very low birthweight, and the preterm birth rate?
- # What internal program and external community factors were associated with successful Healthy Start program interventions?

CHAPTER II

THE HEALTHY START PROGRAM

Each of the 15 Healthy Start demonstration programs was locally determined, reflecting the circumstances and resources available in its community. Based on the program principles outlined above, the Healthy Start programs were given flexibility and encouragement to develop diverse interventions, as long as these interventions were tied to the demonstration goals of reducing infant mortality and improving maternal and infant health. This approach led to programs that included both service delivery and system change components.

The discussion below describes in detail the service delivery and system change components of Healthy Start, based on information from an extensive process analysis of the program. This process analysis included two site visits to each Healthy Start program, two sets of telephone interviews, focus groups with Healthy Start clients and providers, and review of program documents. During the site visits, evaluation staff interviewed program staff, service providers, and consortia members, using semistructured protocols to ensure that the information gathered across programs was comparable. Site visitors also attended consortia meetings, observed health education classes, reviewed case records, and conducted home visits with program staff. In addition to serving as a data source for this report, process analysis data were used for several, separate reports from the national evaluation. A detailed look at the specific program interventions is presented in these reports (Howell et al. 1994; Howell et al. 1997; Baltay et al. 1997; Harrington et al. 1998; and Devaney et al. 1999), as well as in several HRSA reports (including McCann et al. 1996; and Simon and Raykovich 1995).

HEALTHY START SERVICE DELIVERY INTERVENTIONS

The service delivery component of Healthy Start fell into three categories of interventions: (1) outreach and case management services designed to identify, enroll, and monitor women and infants; (2) a network of support services that included health education, transportation, child care, employment assistance, and mental health and substance abuse counseling; and (3) enhancements to available clinical services.

Outreach and Case Management

From its inception, the Healthy Start program emphasized the importance of linking low-income women and their families to needed services. Needs assessments conducted during the first year of the demonstration period indicated that the supply of clinical services was adequate but that the greatest need was to link women and their families to available services in an appropriate, effective manner. Case management was the preferred mechanism for satisfying this need. All Healthy Start programs implemented a form of case management.

Core Functions of Healthy Start Case Management. Case management in Healthy Start included four core functions: (1) initial contact or outreach; (2) intake; (3) assessment, care planning, and referrals; and (4) ongoing contact and tracking. The case management process began when an outreach worker or case manager made *initial contact* with a pregnant woman or mother of an infant. To engage potential clients, Healthy Start programs employed outreach strategies such as intensive door-to-door canvassing, periodic targeting of housing units, canvassing of community/public spaces, community events, telephone contact, mass media campaigns, and hotlines (McCann et al. 1996).

Once outreach activities identified a client, she was introduced to the various services offered by the program and enrolled in Healthy Start case management. The next step in the continuum was *intake* into Healthy Start case management. Intake served two purposes: (1) to orient the woman to Healthy Start and the case management process, and (2) to complete program forms that could be used to track the mother and her infant.

The next step was *assessment, care planning and referral*, which occurred either at the same time and place as intake or during subsequent meetings with the client. In this stage, staff worked with the client (1) to determine her resources and needs (social, medical, and financial); (2) to identify the services available to address those needs; and (3) to develop a plan to access the services she needed.

Once a client was assessed and a care plan developed, staff began to implement the care plan by making appropriate *referrals*. The referral process was informal; programs referred clients based on their knowledge of the existing service network, rather than through formal agreement.

The fourth function in the case management continuum was *ongoing contact and tracking*, defined as monitoring a client's receipt of services and ongoing needs. This function began in pregnancy and continued up to one year postpartum.

Staffing of Healthy Start Case Management. Healthy Start case management used teams of people who were responsible for assessing, tracking, and monitoring the progress of clients and their receipt of services. Three main types of staff served as case managers: (1) lay workers, (2) social workers or similarly trained professionals, and (3) public health nurses.

Lay Workers. In contrast to traditional case management or nurse home visiting programs, Healthy Start case management relied heavily on lay workers. These staff were community residents without professional training, but who received training either on the job or through

special Healthy Start training programs. These workers were familiar with the neighborhood S its residents, resources, and problems.

The use of lay workers had its benefits and disadvantages. Healthy Start program staff felt that the use of lay workers was important for identifying pregnant women and designing and targeting effective interventions. Lay workers were less costly than other professionals, thereby allowing the programs to hire more lay workers than other professionals for a given level of resources. However, lack of specific education in case management or social work posed problems for particular functions of case management (for example, needs assessment and care planning) and for ensuring appropriate documentation in the client record (such as immunization records). Also, lay staff required closer supervision to ensure that case management protocols were understood and followed. To address this concern, lay workers were included in teams with professional workers.

Social Workers. Given the high-risk nature of the Healthy Start population and the complexity of case management, programs relied on social workers or counselors for most core case management functions. Social workers were part of a team with other case management staff, which included lay workers or specialists in mental health, substance abuse, and early intervention.

Public Health Nurses. Three programs used public health nurses, or other nurses with specialized training, to serve as case managers, thus adding a clinical element to case management services. Nurse case managers worked closely with lay and other professional workers to provide a range of clinical and social services to Healthy Start clients.

Implementation of Healthy Start Case Management. Healthy Start was successful in establishing case management programs. In fiscal year 1996, the 11 Healthy Start programs with valid case management data provided case management services to 15,631 maternal clients or to approximately 20 percent of eligible pregnant women living in the project areas (Devaney et al. 1999).

Healthy Start demonstrated that including community lay workers as members of case management teams was feasible and helped identify high-risk women and enroll them in case management programs. In addition, programs that relied primarily on lay workers increased the employment of community residents, thus investing in the community and facilitating community buy-in and support for Healthy Start.

Advocacy for the client was a particularly strong area of Healthy Start case management. Healthy Start clients participating in focus groups frequently mentioned the role case managers played in advocacy on their behalf. Referrals also were an important component of Healthy Start case management, as shown by a review of case management records during site visits to each program.

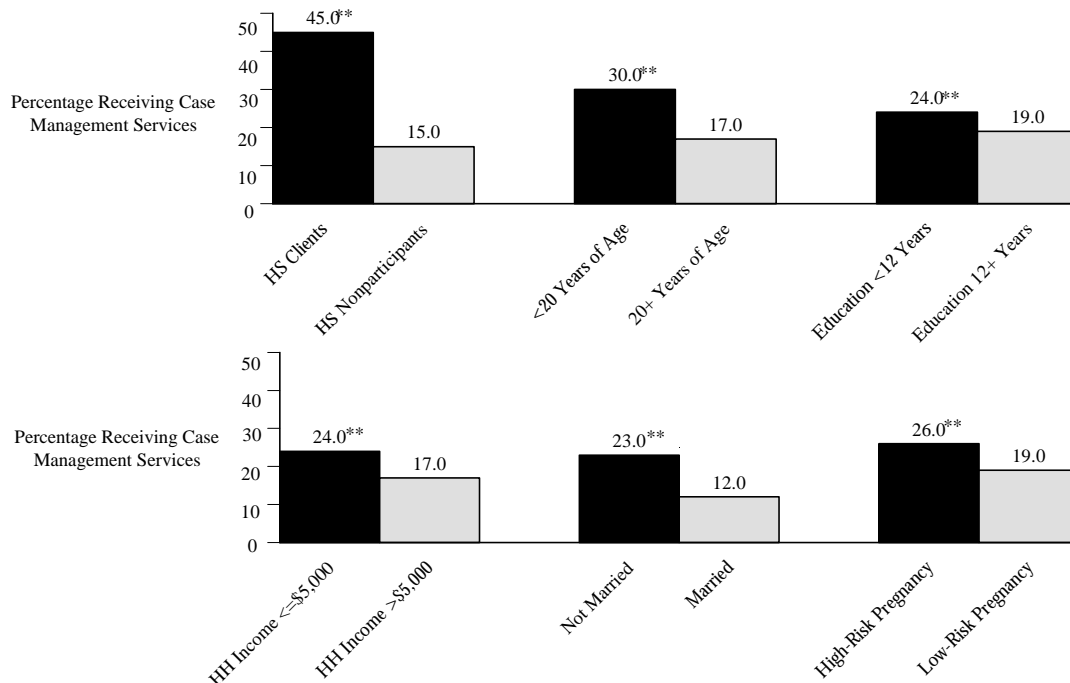
Healthy Start was less successful in implementing, or less successful in documenting, the case management component of ongoing contact and tracking. In particular, while the case management programs identified resources available to clients within the community, they were not able to monitor a client's receipt of services and ongoing needs. A review of case management records in each Healthy Start program revealed numerous referrals for an array of

services but a lack of information on whether the services actually were received. This lack of follow-up information left case managers unable to track whether their clients received needed services; it also prevented programs from fully assessing the impact of their case management programs. Tracking referrals is a problem common to many case management or home visiting programs.

The case management records also showed the difficulty in maintaining or engaging clients in the Healthy Start program. In most programs, the records documented repeated attempts to contact clients, either by telephone or by home visits, with few successes. As reported to the site visitors, one of the biggest challenges to the case managers was scheduling home visits and making sure clients were at home for the visits.

Use of Case Management Services. Based on interviews from a postpartum survey of women living in the Healthy Start project areas, the evaluation examined the use of case management by pregnant and postpartum women living in the Healthy Start project areas. Healthy Start clients were more than three times as likely as other women living in the project areas to receive prenatal case management services (45 percent versus 15 percent) (see Figure 2).

Figure 2
Utilization of Prenatal Case Management Services



Source: Healthy Start Postpartum Survey, 1996.
*(**): $p < .05(.01)$.

Healthy Start was successful in targeting case management services to high-risk women. Women at higher socioeconomic risk were more likely than low-risk women to receive case management services. The percentage of pregnant women receiving case management services was highest for women who were under 20 years of age, had less than a high school education, had annual household income less than \$5,000, or were unmarried (see Figure 2). In addition, women with high-risk pregnancies were more likely than other women to receive prenatal case management services.

Table 2 contains tabulations on characteristics of case management services received by Healthy Start clients. More than 55 percent of Healthy Start clients (56.4 percent) reported two or more prenatal care home visits, and more than one-quarter of the women (26.4 percent) had six or more home visits during pregnancy. On the other hand, over 40 percent of the women (41.7 percent) had either no prenatal home visits or one home visit. For postnatal case management, more than half the women (52.9 percent) reported either zero or one home visit. These figures support one of the primary findings from the review of case management records during site visits: there was a group of clients who were hard to engage and reach through home visits. As documented in the case records, many of numerous attempts to contact Healthy Start clients and schedule a home visit were not successful. This difficulty in maintaining contact with clients was corroborated during interviews with case managers and focus groups with Healthy Start providers.

Table 2: Case Management Services Received by Healthy Start Clients

	Prenatal Case Management (%)	Postnatal Case Management (%)
Number of Home Visits		
No home visits	25.2	9.2
1 home visit	16.5	43.7
2 to 5 home visits	30.0	37.3
6 or more home visits	26.4	9.7
Missing	1.9	0.1
Type of Help Received		
Checked mother's health	66.7	62.6
Checked baby's health	68.4	82.2
Clothing donations	23.3	18.0
Assistance with WIC	19.3	14.3
Food assistance	14.3	12.2
Assistance with Medicaid	13.8	11.3
Assistance with Food stamps	13.1	10.5
Case Management Services Were Very or Extremely Helpful	84.7	82.9

SOURCE: Healthy Start Postpartum Survey 1996.

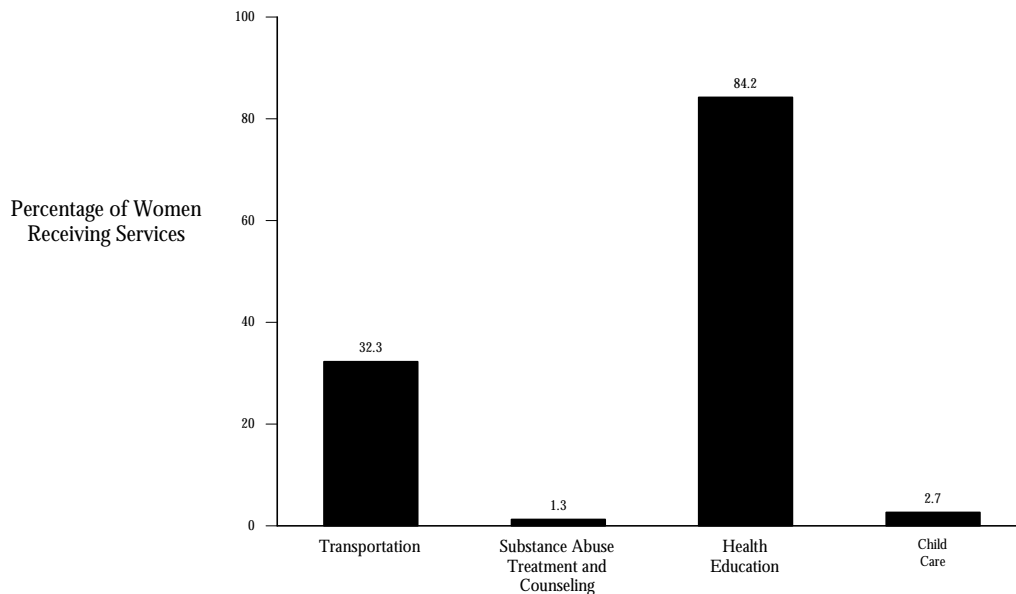
The most common case management service received was checking the mother's and baby's health. Other types of help received by Healthy Start clients included clothing donations, food assistance, and assistance in applying for WIC, food stamps, and Medicaid. More than four out of five Healthy Start clients (84.7 percent) reported that case management services were very or extremely helpful.

Support Services

In addition to case management services, Healthy Start provided a wide range of support services. These services included transportation assistance, substance abuse counseling and treatment, health education, and child care. Figure 3 shows the percentage of Healthy Start clients receiving these services.

Figure 3

Utilization of Healthy Start Support Services



Source: Healthy Start Postpartum Survey, 1996.

Transportation Assistance. Healthy Start programs provided transportation assistance to reduce an often formidable barrier to service, and 32.3 percent of Healthy Start clients reported receiving transportation assistance. Transportation was particularly important in some nonurban or rural areas (for example, Northern Plains and Pee Dee), where public transportation was scarce. For example, 60 percent of Healthy Start clients in the Northern Plains project area received transportation assistance (Howell et al. 1999). The types of transportation services varied from program to program. Many programs provided transportation directly, generally through a “baby van” owned by the program or by contracting for the service. Other programs passed out transportation vouchers for the existing public transportation system.

Substance Abuse Counseling and Treatment. All Healthy Start programs had substance abuse interventions. The form of the intervention varied greatly. Some programs made special arrangements for “slots” in treatment programs, whereby Healthy Start clients received priority for admission. Other programs had a special outreach and referral process for substance-abusing women that was integrated with the case management efforts for all women. These programs either gave special training to case managers or they co-located specialists with those workers. During site visits, program staff reported difficulty finding adequate treatment programs, since the supply of substance abuse treatment was inadequate.

Health Education. Health education was the most common support service and a primary element of case management. More than 80 percent of Healthy Start participants (84.2 percent) reported that they received health education. Topics addressed both the medical and the social factors that were expected to influence infant mortality in the community. All Healthy Start programs offered education on family planning, nutrition, alcohol and drug use/abuse, smoking cessation, and childbirth preparation. More than two-thirds of the Healthy Start programs offered education on parenting, sexually transmitted diseases, infant and child development, domestic and community violence, and breastfeeding. One-third of programs also provided education on stress management, life skills, male/father involvement, literacy, and employment. Other topics included abstinence, sudden infant death syndrome, fetal alcohol syndrome, and lead poisoning.

Healthy Start programs delivered health education through two means: health education classes and one-on-one contact during case management and home visits. As reported in the postpartum survey, Healthy Start clients were more than twice as likely to have received one-on-one health education than to have participated in a health education class (Harrington et al. 1998).

Site visitors observed health education classes at each program site, interviewed program staff about health education, and reviewed all health education materials. As judged by site visitors, the quality of Healthy Start health education varied widely across program areas. This variation in quality depended primarily on the extent to which the programs standardized their health education programs. Programs that used fewer contracting agencies and employed their own health education staff had more standardized and high-quality health education programs. Programs that used multiple contractors were able to exert less control over their health education programs, resulting in less standardization and quality control across program sites.

Program staff noted that maintaining consistency and quality control over health education was challenging because so much of the health education was delivered in one-on-one settings, often by lay case managers.

According to program staff, clients liked receiving information on sexually transmitted diseases. Staff perceived clients as placing lower priority on education in alcohol and drug abuse. Project staff also reported that engaging clients in health education required creativity and persistence. The demands of personal and family responsibilities often took precedence over health education classes. Programs used financial and other incentives to encourage clients to attend health education classes.

Child Care. Healthy Start child care services ranged from providing funds for the development of child care areas in clinics to hiring staff who provided child care. Nine Healthy Start programs used Healthy Start funds to add child care areas in clinics. These areas included either play areas with toys as part of a waiting room or separate rooms with staff to watch the children while their mothers had their prenatal care visit. In Oakland, for example, child care workers were hired to care for children on a drop-in basis while Healthy Start clients attended classes.

Other Support Services. Support services offered by Healthy Start programs included literacy training, employment and training services oriented toward developing self-sufficiency, housing assistance, other emergency assistance, mental health services, grief counseling, male partner programs, and adolescent education and empowerment programs. Local evaluations provide additional information on these services.

Enhancements to Clinical Services

All Healthy Start programs provided, directly or through contracts, clinic services to infants and pregnant women. Rather than develop new facilities, Healthy Start programs modified or enhanced the existing delivery system for prenatal, postpartum, and infant care.

Table 3 provides an overview of the enhanced clinical services funded under Healthy Start. Across 14 of the 15 project areas, 167 care delivery sites received Healthy Start funds. The average amount received was about \$75,000. Larger grants were provided by the Healthy Start programs in Northwest Indiana and Oakland, which established “one-stop shopping centers” and where clinical services were provided in conjunction with other Healthy Start services.

The Medical Reform Initiative in Baltimore was an example of a comprehensive effort to improve the existing clinic system. Each provider that received Baltimore Healthy Start funds had to make wide-ranging improvements in its prenatal and infant care programs, such as reducing waiting times for appointments, involving male partners, soliciting feedback on patient satisfaction, providing health education, and adding child care areas.

Healthy Start programs also used grant funds to hire additional clinical staff or to provide more competitive salaries. Additional clinic staff included obstetrician/gynecologist providers, pediatricians, and nurses, particularly nurse midwives and nurse practitioners. Also hired with Healthy Start funds were nutritionists, phlebotomists, nursing assistants, and clerks. The additional personnel hired by Healthy Start funds were expected to improve the quality of services and to increase clinic capacity.

Table 3: Enhancements to Clinical Services Funded by Healthy Start

Project	Number of Clinical Provider Sites Funded by Healthy Start	Clinical Expenditures in FY 1996 (\$1,000s)	
		Total	Average per Provider
Baltimore	14	\$1,437	\$103
Birmingham	7	534	76
Boston	1	56	56
Chicago	16	1,879	117
Cleveland	3	156	52
Detroit	5	648	130
District of Columbia	11	1,321	120
New Orleans	8	1,226	153
New York	26	382	15
Northwest Indiana	3	569	189
Oakland	14	2,213	158
Pee Dee, SC	22	944	43
Philadelphia	22	1,072	49
Pittsburgh	15	109	7
Total	167	\$12,546	\$75

SOURCE: Number of providers: Site visits, January-March 1996.

Expenditures: Special FY 1996 expenditure report prepared by programs in late 1996.

NOTE: Data were not available for Northern Plains.

HEALTHY START SYSTEM CHANGE INTERVENTIONS

Healthy Start focused on improving systems of care in the communities serving low-income, high-risk women and their families. Mechanisms to accomplish this included public information campaigns, service integration and coordination, management information systems, and infant mortality reviews.

Public Information

One objective of the Healthy Start program was to increase community awareness of infant mortality and its causes. To accomplish this objective, the Healthy Start program featured both national and local public information components. The purpose of public information was threefold:

- # To increase awareness in the community (consumers, providers, businesses) of the presence and adverse impact of infant mortality
- # To elicit community interest and participation in the local Healthy Start program
- # To promote healthy behaviors among women of childbearing age

The public information activities of Healthy Start were among the most interesting of all program efforts, and site visitors ranked programs highly on these efforts. At the national level, Healthy Start conducted three waves of public information and education campaigns using national television, radio, posters, and billboards. For example, the third wave of public service advertisements, released in February 1997, urged women to avoid putting their babies' health "on the line" by seeking early and regular prenatal care. The campaign featured toll-free numbers for English- and Spanish-speaking callers. At the local level, each Healthy Start program implemented programs to promote prenatal care and encourage the use of services. Programs used a mixture of strategies, such as local television and radio public service announcements, newsletters, and other educational materials.

HRSA contracted with Vanguard Communications to assist with the national campaign and to provide technical assistance to each program in planning and implementing its public information program. To help programs share their ideas, Vanguard organized regular telephone conference calls and published a newsletter.

Service Integration and Coordination

Another objective of Healthy Start was to improve the service delivery system for women and infants. Table 4 shows the number of providers in the 14 Healthy Start project areas with available data. Healthy Start funded 698 providers; more than 800 others were in the referral networks of the programs. Clinical providers comprise the bulk of the Healthy Start network. Through its funding of 167 clinical providers, Healthy Start was clearly successful in enhancing the clinic provider network. Healthy Start also increased the network for three key support services: transportation (60 providers funded through Healthy Start), substance abuse services (70 Healthy Start providers), and health education providers (129 Healthy Start providers).

Programs coordinated their services in several ways. First, service delivery networks were created to improve linkages among maternal and child health services. These networks were developed through formal referral arrangements or through informal referral patterns that were encouraged and enhanced by the Healthy Start case management process. Second, one-third of Healthy Start programs coordinated services through co-location. Third, programs approached service coordination through improved data linkages.

Management Information Systems

The Healthy Start programs received funding to develop a dual-purpose management information system that would (1) improve internal management, and (2) meet federal reporting requirements for providing data to HRSA and the national evaluation. The 15 programs together spent more than \$6 million in fiscal year 1996 on their systems, accounting for slightly more than six percent of total Healthy Start expenditures.

Despite technical assistance and the relaxation of data collection requirements, all programs struggled to implement a system that met HRSA requirements for a Minimum Data Set (MDS). One common problem was that the programs could not collect much of the required data, particularly the clinical data. For example, existing providers delivered clinical services to Healthy Start clients. Healthy Start was a small part, if any, of the funding for those providers, who, consequently, had little incentive to comply with data collection requirements.

Table 4: Healthy Start Service Provider Network

Project	Total Providers		Clinical Providers		Selected Support Services					
					Transportation		Substance Abuse Services		Health Education	
	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS
Baltimore	55	101	14	4	2	1	4	46	13	21
Birmingham	24	41	7	9	3	4	1	2	7	8
Boston	59	12	1	11	12	0	3	0	22	0
Chicago	59	44	16	12	5	1	9	2	7	4
Cleveland	36	106	3	13	3	4	2	23	2	12
Detroit	24	28	5	8	1	1	1	5	8	7
D.C.	38	25	11	11	4	0	5	5	6	2
New Orleans	21	23	8	10	2	0	2	2	1	1
New York	97	173	26	85	6	0	12	23	12	11
Northwest Indiana	25	34	3	10	3	1	4	5	6	3
Oakland	45	39	14	18	2	0	5	3	5	9
Pee Dee, SC	80	60	22	19	12	0	12	7	13	7
Philadelphia	56	60	22	4	3	2	2	17	11	8
Pittsburgh	79	63	15	43	2	0	8	3	16	10
Total	698	809	167	257	60	14	70	143	129	103

SOURCE: Site visits, January-March 1996.

NOTE: The sum of the provider categories does not equal the total, as other smaller service categories were in the total network but are not listed in the table (see Howell et al. 1997). Data were not available for Northern Plains.

HS: Healthy Start funded providers.

Not HS: Providers not funded by Healthy Start.

A second problem was the sheer volume of information required. In an attempt to have good program data, the MDS originally included an extensive maternal data set that included 241 variables on 12 topics and an infant data set that included an additional 159 variables on 8 other topics.

Another impediment to system development was the absence of data collection protocols. There were no standard forms for data collection or standard definitions for where data should be captured (for example, from the medical record, vital statistics, or interviews with program clients or providers). This led to a lack of comparability across programs.

In retrospect, it would have been preferable to develop standard data collection protocols and a data processing software package for programs to use at the beginning of the demonstration. However, this would have been difficult, given the diversity of Healthy Start programs and the lack of knowledge about the types of providers when the data set was developed. In the end, despite significant expenditures, the MDS data were incomplete and could not be used for program monitoring, federal reporting requirements, or the national evaluation.

Infant Mortality Review

Infant mortality reviews (IMRs) were designed to assist programs in identifying the factors contributing to infant mortality in their project areas. In this program component, infant deaths

were reviewed by committees to (1) determine the clinical, social, and health factors contributing to an individual death; and (2) make recommendations to improve infant outcomes.

Most IMRs had a two-tiered structure consisting of a technical review panel, which conducted a medically oriented review, and a community panel, which provided social focus. The material presented to the panels consisted of summaries of data derived from abstraction of medical records, social services records, coroners' and autopsy reports, police reports, health department records, and maternal interviews.

The Healthy Start IMR model has been appreciated by programs as a tool for characterizing local causes of infant mortality. The IMR efforts have yielded valuable information on the preventable causes of infant death that can form the basis for meaningful program and policy recommendations.

Productivity of the IMR process varied across programs, ranging from record abstraction for 14 percent through 100 percent of all infant deaths in the project area and maternal interviews for less than 1 percent through 79 percent of infant deaths. Program staff reported that the IMR process, as implemented, often did not provide a mechanism for prioritizing recommendations and implementing them.

HEALTHY START PROGRAM ADMINISTRATION

To implement the program interventions, Healthy Start grantees developed a variety of administrative arrangements. The most common location for a Healthy Start grantee (7 of 15 sites) was within a city health department. In addition, three grantees were located within county health departments, and one was within the state health department.

As reported by program staff during evaluation site visits, reliance on health departments for administrative oversight provided several advantages:

- # Health departments all had qualified staff to oversee initial program development.
- # Health departments were tied directly to a jurisdiction's political and health care leadership, a relationship that encouraged the support and involvement of such leaders.
- # Health departments often helped sustain certain components of the program when federal funding declined.

Location within a health department also had disadvantages, as reported to the evaluation staff:

- # Civil service procedures slowed hiring and contracting for services, thus impeding the early startup of a demonstration program.

-
- # Poor relationships in some programs between the local population, or providers, and the health department affected implementation.

To avoid these disadvantages, four of the health department grantees (Baltimore, Boston, New Orleans, and Pittsburgh) contracted with private, nonprofit entities to administer the Healthy Start program. While the grantees contracted with such organizations to operate Healthy Start, line authority for the program remained with the health department. In addition, in four programs (New York, Northern Plains, Northwest Indiana, and Pee Dee), the grantee itself was an existing nonprofit organization.

As part of the process analysis for the national evaluation, site visitors examined the strength of each project's program administration on the following dimensions:

- # Stability of the grantee agency staff
- # Stability of the Healthy Start program staff
- # Ease of recruitment of initial and replacement staff
- # Stability of the Healthy Start organizational structure
- # The project director's leadership, political, and managerial skills
- # Managerial support from the grantee agency for the program
- # The degree to which the program staff and grantee agency staff worked together
- # Flexibility to allow for changes in program implementation when required
- # Strong contract monitoring for program components that were implemented through contracts

After completion of the site visits and telephone interviews, site visitors ranked programs according to each of these dimensions of program administration. Five programs **S** Baltimore, New Orleans, New York, Oakland, and Pittsburgh **S** were administratively strong across these dimensions.

Site visitors observed that seven of the Healthy Start programs had difficulty hiring and retaining staff (Howell et al. 1997). Program staff reported bureaucratic delays in the hiring process as the major source of difficulty. Stability of the Healthy Start program staff was also key to program administration, and in six programs, staff turnover was a problem.

HEALTHY START EXPENDITURES

At the federal level, the funding appropriated for Healthy Start was substantially less than anticipated during the application and planning process, and the number of grantees was greater. Programs originally expected up to \$2.5 million for the planning phase, but actual awards were between \$1.2 and \$1.8 million. The federal budget request for second-year appropriations was \$171 million for an expected 10 programs, whereas actual grant awards totaled \$59.7 million for 15 programs. As a result, most grantees developed their Comprehensive Healthy Start Plan and defined their project areas with the expectation of substantially greater funding levels than eventually materialized.

Total funding for the original 15 Healthy Start project areas through fiscal year 1996 (the period covered by the national evaluation) was \$345.3 million. Table 5 shows the grant awards for the demonstration period, fiscal years 1992 through 1996. In the fiscal year 1997 budget, Congress appropriated \$96 million to continue the existing Healthy Start programs for a sixth year, one year beyond the original five-year time frame. Congressional support for Healthy Start remains high. The original 15 project areas have continued to be funded, although at a reduced level, and additional programs have been added. The fiscal year 2000 budget includes \$90 million in funding for 94 Healthy Start programs.

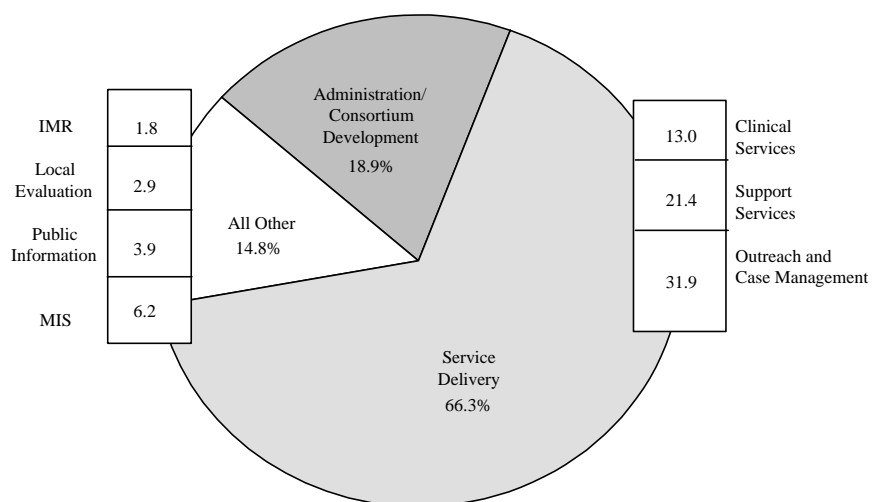
Table 5: Healthy Start Grant Awards (in millions of dollars)

Project Area	FY 1992-1996
Baltimore	28.6
Birmingham	13.8
Boston	27.0
Chicago	28.4
Cleveland	23.5
Detroit	17.1
District of Columbia	23.5
New Orleans	26.1
New York	30.0
Northern Plains	16.7
Northwest Indiana	15.6
Oakland	24.4
Pee Dee, SC	22.0
Philadelphia	25.7
Pittsburgh	22.9
Total	345.3

In fiscal year 1996, expenditures for the 15 Healthy Start programs fell into three categories: (1) service delivery; (2) administration and consortium development; and (3) other system change interventions. Figure 4 shows how these program expenditures were distributed across the three categories. Approximately two thirds (66.3 percent) of total Healthy Start expenditures went to service delivery; 18.9 percent went to administration and consortium development; and the remaining 14.8 percent went to the other categories, which included the infant mortality review, local evaluation, public information, and management information systems.

Figure 4

Healthy Start Expenditures by Expenditure Category Fiscal Year 1996



IMR: Infant Mortality Review
MIS: Management Information Systems

CHAPTER III

COMMUNITY INVOLVEMENT IN THE HEALTHY START PROGRAMS

One of the guiding principles of the Healthy Start program was to include the community in the planning process. All programs encouraged community involvement. In general, community involvement in Healthy Start was accomplished through two main strategies--the consortia and community empowerment (Howell et al. 1998). Healthy Start grantees were required to establish consortia of community leaders, community residents, medical and social service providers, and community organizations to plan and implement the program services. Community empowerment efforts included neighborhood-based consortia, employment, contracts, and economic development efforts. All programs used a combination of consortia and community empowerment strategies.

HEALTHY START CONSORTIA

Healthy Start programs invited a range of people to join their consortia S providers, representatives of government agencies, Healthy Start clients, and community residents. This broad approach to forming consortia affected their size, governing style, and structure. Eight of the Healthy Start programs had consortia with 75 or more members (see Table 6) and functioned more as "town meetings" for disseminating information than as decision-making bodies, especially early in the program period. Other programs created smaller consortia better suited to decision making. Pittsburgh Healthy Start formed an 18-member board of directors, and Pee Dee Healthy Start organized a 14-member regional council. Cleveland had an executive council, an administrative management group, committees, and several local (neighborhood-level) consortia but no large central consortium. In Birmingham, in June 1996, conflict between a small number of consortium members and staff led to dissolution of the large central consortium. Thereafter, a small committee acted as liaison between staff and the community.

Involving providers in the consortia was much easier than involving other community members or key political figures, partly because those who provided services funded through Healthy Start had a greater stake in the program and saw consortia involvement as a way to protect their interests. In fact, more than half S and, in some programs, all S the people at the meetings attended by the national evaluation team were providers.

Table 6: Healthy Start Consortia

Project Areas	Number of Active Committees ^a	Number of Consortia Members	Number of Committee Members	Frequency of Meetings		Forum for Decision Making
				Consortia	Committee	
Baltimore	3	120	10-20	Quarterly	Bimonthly	No
Birmingham ^b	1	None	9	n.a.	Bimonthly	No
Boston	6	300	30	Monthly	Monthly	Yes
Chicago	7	96	10	Bimonthly	Monthly	Yes
Cleveland ^c	9	None	15-20	n.a.	Monthly	Yes
Detroit	3	50	8-20	Bimonthly	Bimonthly	No
District of Columbia	6	169	6	Quarterly	Quarterly	No
New Orleans	7	86	5-34	Quarterly	Quarterly	No
New York	5	100	6	Quarterly	Monthly	Yes
Northern Plains ^d	4	15	15	Annually	Annually	No
Northwest Indiana	3	78	4	Monthly	Monthly	No
Oakland	2	12	12-20	Monthly	Monthly	Yes
Pee Dee, SC	3	14	5	Monthly	Monthly	Yes
Philadelphia	8	150	8	Quarterly	Bimonthly	No
Pittsburgh	6	18	20	Monthly	Monthly	Yes

SOURCE: Second round of site visits, January-March 1996, and telephone updates in May-June 1997.

n.a. = not applicable.

^aDefined as having met at least once in the quarter preceding the site visit or telephone update.

^bBirmingham did not have an active consortium; the consortium was disbanded in June 1996. Thereafter, a small committee provided liaison between staff and community.

^cIn Cleveland, work was done by committees and local consortia.

^dNorthern Plains had one central consortium and four state consortia.

Difficulties involving community members in the consortia occurred despite concerted efforts by many programs. Strategies to increase involvement included reimbursements for meeting-related travel and child care expenses. Persuading people to volunteer meant convincing them of the benefits of their efforts. Focus groups with Healthy Start clients found that infant mortality was not as personally compelling to community residents as other community issues such as poor housing, unemployment, and violence.

After the initial start-up phase of Healthy Start, much of the work of the consortia moved to committees. The committees were more effective decision-making entities because they were smaller.

HEALTHY START COMMUNITY EMPOWERMENT

All programs adopted community empowerment strategies to involve the community in the Healthy Start program. Community empowerment had four main strategies: (1) engaging

III. Community Involvement in the Healthy Start Programs

people in planning efforts through local consortia, (2) contracting with community-based organizations for services, (3) employing community residents as lay workers in the Healthy Start programs, and (4) creating other economic development activities.

The first strategy was to build local consortia with representation from the community and consumers. Eleven programs created local consortia consisting of neighborhood residents and local providers. Local consortia became forums for information sharing and community health education. These consortia had special responsibilities, such as recommending community applications for program funding. They often handled small budgets to fund Healthy Start-related community events, such as health fairs and other outreach activities.

The effort to develop grassroots community involvement was intensive. Program staff needed to identify local residents as potential members, recruit them, develop meeting agendas and locations, attend meetings, and prepare minutes and reports. Local consortia that became active required substantial staff effort. In addition to the energy needed to organize the group, the ability to galvanize neighborhood support around issues was a necessary and special skill.

A second strategy in the community empowerment model was to contract with community-based organizations, such as nonprofit agencies or businesses in the service area that were closely tied to the community. Boston, for example, had 51 contracts with community-based organizations, and Philadelphia had 65 (Table 7).

As reported during site visits, contracting with community-based organizations was a challenge. Because of limited administrative resources, staff of community-based organizations had little time to write grant proposals or to prepare progress and financial reports. Local Healthy Start program staff often had to provide technical assistance in grant proposal writing. Program staff also reported the need to modify standards used for oversight or contract monitoring for very small grantees.

In addition to using local consortia and community-based organizations, all programs employed community residents (Table 7). Programs that hired large numbers of residents also defined a career path for them. For example, some community outreach workers were trained to deal with substance abuse, while others were promoted to outreach worker supervisors. Programs successfully hired and trained former welfare recipients, and worked closely with local employment and job training programs, such as those funded through the Job Training Partnership Act (Simon and Raykovich 1995).

SUMMING UP

Community involvement was a guiding principle of Healthy Start. The national evaluation identified the following lessons from Healthy Start on community involvement:

- # It was difficult to involve community residents in grassroots efforts, and the Healthy Start programs used different approaches.
- # Efforts to involve the community were extremely labor-intensive for program staff members, providers, and community residents. Job creation appeared to be the best way to involve community residents.

Table 7: Healthy Start Community Empowerment

Project	Number of Active Local Consortia	Number of Contracts with Community-Based Organizations	Number of Lay Outreach/ Case Management Workers Employed
Baltimore	2	16	95
Birmingham	1	13	22
Boston	0	51	n.a.
Chicago	1	17	60
Cleveland	11	4	97
Detroit	3	12	16
District of Columbia	0	13	36
New Orleans	9	10	101
New York	3	27	25
Northern Plains	19	0	39
Northwest Indiana	4	5	18
Oakland	3	21	7
Pee Dee, SC	6	37	4
Philadelphia	0	65	16
Pittsburgh	6	11	22

SOURCE: Second round of site visits, January-March 1996, and telephone updates, May-June 1997.

n.a. = not applicable.

- # Residents and providers were motivated to change their communities, and they participated if given appropriate incentives.
- # Given financial incentives, it was easier to involve community providers than community residents and nonprofessionals.
- # Community involvement may impede efficient program operations. In some programs, for example, the involvement of consumers and providers necessitated additional time for the implementation of structured service protocols, lay-professional teams, contract monitoring, and quality assurance procedures.
- # Community involvement itself is a developmental process and may slow program implementation. Therefore, evaluations that are designed to measure short-term outcomes may not capture the full impact of community involvement strategies.

Despite some difficulties, the Healthy Start programs have shown a true commitment to and some success with community involvement.

III. Community Involvement in the Healthy Start Programs

CHAPTER IV

THE HEALTHY START TARGET POPULATION AND PROGRAM CLIENTS

All pregnant and postpartum women and all infants residing in the project areas constitute the Healthy Start target population. Only a subset of the target population, however, are program clients served by the direct service delivery component of Healthy Start. For better understanding of the implementation of Healthy Start and its effects on outcomes, this chapter describes both the target population and program clients.

DATA SOURCES

Four data sources are available to describe the characteristics of the Healthy Start target population and program clients served: (1) vital statistics data for the full Healthy Start target population; (2) the Minimum Data Set on program clients; (3) the Healthy Start Postpartum Survey of program clients and nonparticipating women; and (4) focus groups conducted with selected Healthy Start providers and program clients in each project area.

The *vital statistics data* are the best source for examining the characteristics of the Healthy Start target population. These data have been compiled for each of the project areas, from 1984 (depending on availability) through 1996, and include information on each birth and death in the Healthy Start project area during this time period. The birth certificate file contains a consistent set of information across project areas on maternal and paternal characteristics, the timing and extent of prenatal care, pregnancy history, basic demographic characteristics, and birth outcomes.

The *Minimum Data Set* (MDS) was a required set of data elements to be collected for each Healthy Start client. The MDS was designed to serve the dual purpose of improving program monitoring and management and of meeting federal reporting requirements. As mentioned previously, difficulties encountered by the programs in implementing an efficient management information system impeded the development of accurate program statistics across the 15 Healthy Start programs. Data for fiscal year 1996 can be used to provide information on counts of maternal and infant clients. Service delivery information, however, is incomplete and cannot be used to describe the services received by Healthy Start participants.

The *Healthy Start Postpartum Survey* was a cross-sectional survey of postpartum women living in the 15 original Healthy Start project areas. The survey was designed to capture the breadth of the prenatal and postpartum experiences of a representative sample of women living in the project areas. In-person interviews were conducted with a sample of 2,851 women whose infants were receiving services from the Supplemental Nutrition Program for Women, Infants, and Children (WIC), including 1,447 Healthy Start clients and 1,404 nonparticipants who resided in the 15 Healthy Start project areas between December 1995 and April 1996. The questionnaire included six general topic areas: (1) prenatal care; (2) labor, delivery, and postpartum care; (3) Healthy Start services; (4) case management and home visits; (5) family planning; and (6) demographic characteristics and other life factors.

The Healthy Start postpartum survey is a good source of data for looking at the characteristics of Healthy Start clients and how they differ from nonparticipating women and infants. In addition, the survey data provide information on the services received by Healthy Start clients and nonparticipants, as well as the effects of Healthy Start on health outcomes. Program-specific analyses, however, could not be conducted due to small program-specific sample sizes.

Qualitative data from *focus groups* round out the data sources on Healthy Start clients. As part of site visits to each of the 15 programs during 1996, focus groups with Healthy Start clients provided in-depth qualitative information on the program. Clients were asked about their lives, children, and experiences during pregnancy; how they learned about Healthy Start and what prompted them to get involved; how Healthy Start helped them and how it differed from other services available in their community; and how the program could be improved.

A total of 26 focus groups with 165 Healthy Start clients were conducted across the 15 project areas. Focus group members were selected by local program staff in consultation with the national evaluation team. The focus groups provided a glimpse into the lives and circumstances of program clients, and described the impact of Healthy Start on their lives.

HEALTHY START TARGET POPULATION

The Healthy Start target population was a high-risk group. Looking at the mothers of infants born in the Healthy Start project areas, 22.7 percent were under age 20, 35.5 percent had not finished high school, 84.5 percent were members of a racial or ethnic minority group, and 74.8 percent were unmarried (see Table 8).

The characteristics of the target populations varied across the project areas. For example, in Baltimore 34.2 percent of the mothers were under age 20, compared with 14.2 percent in Boston and 16.8 percent in Oakland. Also in Baltimore, 54.3 percent of the mothers had less than a high school education, compared with 20.1 percent in Pittsburgh. The percentage of women receiving no prenatal care also varied from 0.5 percent in Boston to 7.7 percent in the District of Columbia.

Table 8: An Overview of the Healthy Start Target Population: Mothers of Infants Born in 1996

Project Area	< 18 Years of Age	18-19 Years of Age	< High School Education	No Prenatal Care	African American	Hispanic	Unmarried
All Project Areas	10.3	12.4	35.5	3.4	73.8	10.7	74.8
Baltimore	17.7	16.5	54.3	4.3	96.2	0.3	92.3
Birmingham	11.8	15.4	29.3	2.0	88.1	0.6	67.0
Boston	5.9	8.3	26.3	0.5	52.8	21.0	58.4
Chicago	9.9	13.0	47.9	4.9	59.7	25.1	69.2
Cleveland	12.2	13.1	35.5	2.9	90.6	1.7	80.6
Detroit	9.7	13.3	38.2	4.5	94.8	NA	NA
District of Columbia	10.5	11.3	35.3	7.7	94.3	2.5	82.1
New Orleans	12.7	15.7	41.0	4.6	95.0	1.4	82.4
New York	7.1	10.1	36.9	3.5	64.6	29.1	77.4
Northern Plains	4.4	22.6	37.4	2.6	0.0	0.0	71.4
Northwest Indiana	9.6	13.7	30.6	3.2	51.1	18.2	64.9
Oakland	7.8	9.0	44.5	0.8	40.9	35.4	NA
Pee Dee, SC	10.2	13.8	29.9	1.8	57.4	1.0	NA
Philadelphia	9.6	10.8	26.7	4.5	85.2	1.2	72.7
Pittsburgh	8.8	10.2	20.1	2.7	60.4	0.7	NA
United States	5.1	7.9	22.1	1.1	14.9	18.0	32.4

SOURCE: State vital statistics birth files, 1996; United States totals from Ventura et al. (1998b).

NA = not available.

Enrollment of Healthy Start Target Population

One measure of program implementation is the penetration of the program into the community, as measured by the percentage of the target population who enrolled in the Healthy Start program. For infants born in 1995, the percentage of pregnant women who enrolled in Healthy Start by 33 weeks gestation was, on average, 16.7 percent and ranged from 6.9 to 36.0 percent (Table 9). Adding in mothers who enrolled after 33 weeks gestation (either during pregnancy or after the baby's birth) and infants who enrolled after birth raised the penetration rate to 24.8 percent on average, with a range between 8.8 percent and 59.6 percent.

The Healthy Start project areas were defined during the grant application process, when the expected funding per site was considerably larger than the actual funding turned out to be. One project area (Baltimore) targeted its program to two smaller areas within the original larger project area after the level of funding was less. This project area also had the highest percentage served, clearly reflecting its more targeted service areas.

Table 9: Enrollment of Target Population in Healthy Start, 1995

Project Area	Number of Births, 1995	Percentage of Target Population Enrolling		Total
		by 33 Weeks Gestation	After 33 Weeks Gestation	
Baltimore	1,141	31.7	27.9	59.6
Birmingham	2,912	36.0	14.0	50.0
Boston	4,457	10.0	5.0	15.0
District of Columbia	2,652	15.3	18.6	33.9
New Orleans	3,166	19.6	5.6	25.2
Northwest Indiana	3,761	19.6	2.0	21.6
Pee Dee, SC	3,363	6.9	1.9	8.8
Philadelphia	4,412	10.7	7.0	17.7
Pittsburgh	1,568	16.3	10.5	26.8
Total	27,432	16.7	8.1	24.8

SOURCE: Fiscal year 1996 Minimum Data Set; State vital statistics birth files, 1995.

NOTE: Several programs were not able to provide the national evaluation with a data set of linked MDS and birth records. For these programs, data on the percentage enrolling are not available.

Several issues are important to consider about the estimates of the Healthy Start enrollment rates. First, as noted, data were not available for all project areas. All Healthy Start programs found it difficult to link their birth certificate files for the project areas with their MDS data, and six programs were either not able to accomplish this linkage or the enrollment rates were so low as to raise questions about the quality of the linkage. Second, those programs with the highest enrollment rates were also those with the best data systems. Thus, one possibility for the variation in estimated enrollment rates is that higher enrollment rates simply reflect better data systems.

Healthy Start Program Clients

In fiscal year 1996, Healthy Start served 49,695 mothers and infants, according to MDS data on counts of Healthy Start clients (see Table 10). Project areas varied in the number of clients served \$ from more than 7,000 in Cleveland and Philadelphia to fewer than 1,000 in Pee Dee.

Looking at the characteristics of Healthy Start program clients, Healthy Start was successful at enrolling women with higher risks of adverse pregnancy outcomes. Healthy Start clients were more likely than nonparticipants to be teens, to have less than high school education, to be

Table 10: Number of Healthy Start Maternal and Infant Clients by Project Areas Fiscal Year 1996

Project Area	Maternal Clients ^a	Infant Clients	Total Clients
Baltimore	1,351	679	2,030
Birmingham	2,160	1,822	3,982
Boston	2,557	1,280	3,837
Chicago	758 ^b	1,782	2,540
Cleveland	3,691	3,596	7,287
Detroit	1,306	386	1,692
District of Columbia	2,316	2,316	4,632
New Orleans	1,717	1,038	2,755
New York	1,412	817	2,229
Northern Plains	1,355	985	2,702 ^c
Northwest Indiana	2,558	1,987	4,545
Oakland	1,003	638	1,641
Pee Dee, SC	440	345	785
Philadelphia	3,828	3,301	7,129
Pittsburgh	653	1,256	1,909
Total	27,105	22,228	49,695^c

Source: Fiscal Year 1996 Minimum Data Set.

^aMaternal clients include both those who gave birth during the year and those who were pregnant during the year.

^bChicago project staff noted that their maternal clients are not all included in the MDS due to data system problems.

^cNorthern Plains MDS data included 362 clients who could not be identified as either maternal or infant clients.

African American, to have lower income, and to be unmarried (see Table 11). They were also more likely to have an unintended pregnancy. In regard to prenatal care, Healthy Start clients were less likely to receive care in a private office, relying more on clinics in hospitals or neighborhood health centers. They were also more likely to see a midwife as part of their prenatal care. Finally, the link to the social service system was stronger for Healthy Start clients than nonparticipants; clients were more likely than nonparticipants to receive WIC services during pregnancy and to receive income assistance in the form of food stamps and welfare.

In summary, the Healthy Start programs targeted a high-risk group of women and infants. Healthy Start was successful at identifying and enrolling those of highest risk of adverse outcomes and at linking them to available services.

Table 11: Characteristics of Healthy Start Clients and Nonparticipants		
Characteristics	Clients (%)	Nonparticipants (%)
Sociodemographic Characteristics		
Maternal Age < 20	25.0	15.2**
Education < High School	45.6	36.2**
African American	83.8	66.6**
Household Income < \$5,000	44.6	36.0*
Never Married	67.8	53.9**
Obstetric and Prenatal Care Characteristics		
Parity One	44.2	40.4
Pregnancy Unintended	77.7	71.2*
Private Office for Prenatal Care	18.8	35.9**
Midwife Provided Prenatal Care	41.4	33.6**
No Insurance Coverage	14.4	10.0
Barriers to Prenatal Care	15.2	13.3
Social Service Receipt		
WIC Services During Pregnancy	83.8	77.3*
Receiving Food Stamps	66.5	59.4*
Receiving AFDC	58.1	51.2*

SOURCE: Healthy Start Postpartum Survey 1996.

NOTE: Excludes Northern Plains. See Howell et al. (1999) for a detailed analysis of the Northern Plains postpartum survey data.

*(**): $p < .05$ (.01).

IN THEIR OWN WORDS

Focus groups with Healthy Start providers and program clients provided a description of Healthy Start clients. In general, Healthy Start clients were from an impoverished area, received some form of public assistance, were unemployed, had lower education and little job training or experience, were unmarried, and were raising or expecting to raise their children alone. Some had criminal records, others were homeless, and still others had some form of mental illness or substance abuse problem. Providers reported that younger clients were more likely to have unplanned pregnancies but generally used more support services in the community. Older clients, however, had several children and were more difficult to enroll and maintain in services, in part because they believed they did not need them.

Low Self-Esteem and Uncertainty About the Future. Healthy Start clients reported feeling hopeless and having low self-esteem. Fear, desperation, and poverty were themes that frequently emerged as clients talked about their reaction to pregnancy. Many were very young; they did not intend to become pregnant and were uncertain about their ability to care for and pay for a child.

Healthy Start clients talked about problems related to substance abuse: either their own substance abuse; that of a close relative or male partner; or violence related to substance abuse.

“I was so young I didn’t know what I was going to do.”

“I was real scared...finding out that I was pregnant. My job was just terminated and I didn’t know what else was going to happen. At the time, I had no medical insurance. That’s when I got introduced to the program and they offered me a whole lot of help that I’m real grateful for.”

*“You don’t have a job. You got the bills. You’re like, “Oh my God, the rent.” The lights, the gas, the heat **S** this is stuff that has to be paid. When you get through with this, then you have the babies. You have to take care of your baby. If there isn’t anyone helping you, what are you going to do?”*

“I’m a recovering addict...I am three years clean. To have another baby was just outrageous to me...I was very depressed. I didn’t know how I was going to deal with it. But I’d just like to say that I made the decision to have the baby, and Healthy Start helped me live with it.”

Housing Problems. Healthy Start clients talked about difficulties with inadequate housing and homelessness. In urban areas, they described substandard, unsafe housing, which lacked plumbing and was infested with vermin. The waiting list for subsidized housing was lengthy in the urban project areas. Lack of space in shelters caused homeless clients to seek temporary refuge in abandoned housing. Providers found it difficult to maintain contact with clients who had problems with housing and needed to move in with friends and other family members on a temporary basis.

Rural Obstacles to Care. Clients in rural areas faced different obstacles from their counterparts in urban areas. Isolation, inadequate supply of providers, and limited transportation were some of the difficult problems faced in the two rural programs **S** Pee Dee and Northern Plains. Transportation was an important barrier and one that the programs tried to address:

“Transportation is extremely valuable because a very high percentage of our parents do not have reliable transportation available. There is no public transportation on the reservation, which means you must own a car to get around. A lot of our people don’t own cars. It takes money to own a car. And welfare won’t buy a car. They say, we’ll reimburse you for mileage to take your child up for a medical appointment, but if you don’t have a car how are you going to get there?”

Violence. Residents in all project areas contended with crime, including domestic violence. Drive-by shootings and major problems related to gang violence were common. Drug use, abuse, and trafficking were prevalent. Unintentional injuries, criminal acts, and homicide were a constant threat. Violence was perceived as a problem that affected access to services.

“The whole environment is violence.”

“You can’t walk through the neighborhoods without them having drugs around you.”

Concern for Their Baby. Clients talked about their concern for their health and the health of their baby. They worried about health problems such as gestational diabetes, gallstones, pancreatitis, anemia, high blood pressure, and being underweight. Clients faced other problems as well, such as fear of hospitals, poor eating habits, being unemployed, lacking money or health insurance, having had an abortion, and having lost a child either to death or to the foster care system. They also worried about their parenting knowledge, their ability to love and nurture their children, and their finances.

“I got scared like, will my baby be all right? Will he or she be healthy? Will I be a good mother? It’s one thing to babysit for somebody, but to be a real mother...I’m like, what do I do? How do I know if my baby is sick or colicky? All kinds of stuff were going through my head.”

Resiliency and Determination. In spite of the problems and barriers that women and their families faced, Healthy Start clients appeared to be resilient and determined. They were highly motivated to better themselves and to provide their babies with a better life. Clients expressed a desire to get a decent education and build careers that would support an independent lifestyle, free from the constraints of welfare and other social programs. They stressed the importance of giving children love and respect, providing positive reinforcement, and showing patience. Clients also felt the need to serve as a positive role model for their children. Clients saw Healthy Start as a lifeline to grasp when moving forward with their life.

“I’d like to be a very independent, positive role model for my daughter.”

“I want to become an RN and be independent and make plans for the future.”

SUMMING UP

The profile of the Healthy Start target population and clients is one of young, poor mothers who often have multiple problems and who are in great need of service. They are unsure of their ability to care for and afford their baby, their housing situation is precarious, and they fear the violence and uncertainty in their environment. Most of their pregnancies are not intended. Yet these mothers share an overwhelming concern for their baby and want to be better parents and role models for their children.

CHAPTER V

EFFECTS OF HEALTHY START ON PRENATAL CARE, INFANT MORTALITY, AND BIRTH OUTCOMES

The focus of the Healthy Start program was reducing infant mortality and improving birth outcomes. Through its major interventions of case management and support services, Healthy Start was successful in enrolling women and infants from demographic groups at high risk of adverse pregnancy outcomes. Public information campaigns focused on educating the community on issues closely linked to infant mortality. Infant mortality reviews examined medical and social factors related to infant mortality, communicated findings to the community and to medical professionals, and recommended changes to reduce infant mortality. Finally, systemic changes to the health care system were made to reduce barriers to effective health care utilization and to improve maternal and infant health status.

The outcomes analysis, the focus of this chapter, examined trends in infant mortality, prenatal care utilization, and birth outcomes, as well as the extent to which Healthy Start influenced these trends.

DATA SOURCES AND METHODS

The primary source of data for the outcomes analysis was birth and death files from 1984 through 1996 for the Healthy Start project areas and their matched comparison areas. In 13 of the 15 project areas, the files obtained for the analysis were linked birth and death files, where all infant death records were linked to their corresponding birth records. Linked birth and infant death files are useful, since they can be used to conduct individual-level analyses of infant mortality and to examine factors associated with infant mortality. In two project areas, linked birth and death files were not available. In these two project areas, unlinked birth and death files were used in the outcomes analysis.

The basic strategy underlying the outcomes analysis was to compare infant mortality rates and other birth outcomes **S** over time and for specific project areas **S** with those in carefully matched comparison areas. The evaluation team, in consultation with and after receiving feedback from program staff, identified potential comparison areas and selected those that were the closest match to the Healthy Start project areas. With the exception of Boston, each Healthy Start project area had two matched comparison areas. For Boston, the evaluation team and program staff could define only one matched comparison area.

The Healthy Start project areas and their matched comparison areas were similar in their level of infant mortality prior to Healthy Start. In nearly all instances, the 1989-1991 infant mortality rates for the comparison areas were within 10 percent of the infant mortality rate for the Healthy Start project areas (Moreno et al. 2000). In addition, Healthy Start project areas and comparison areas matched closely in terms of racial and ethnic composition.

The comparison area methodology assumes that carefully matched comparison areas serve as a proxy for what would have happened in the project areas in the absence of the Healthy Start program. Two considerations about this methodology are important:

1. The preferred design for evaluating program impacts is random assignment. This approach, however, is not feasible for evaluating communitywide initiatives such as Healthy Start.
2. Comparison areas also were those communities with high infant death rates and those likely to have other program interventions similar to Healthy Start. Thus, the analysis would be detecting the effects of Healthy Start that differ from those of other program interventions that may have been operating in the comparison areas.

The evaluation team considered this second issue in selecting comparison areas and in conducting and interpreting the analysis. Comparison areas were selected after extensive consultation with program staff. Program staff advised against a particular comparison area if it had a program intervention similar to Healthy Start. In addition, most comparison areas were not contiguous geographic areas or neighborhoods. Indeed, sometimes they were constructed from geographic units from different cities or states. Thus, similar program interventions were unlikely to be operating in an entire comparison area.

In summary, although this methodology has some limitations, the evaluation team took steps to mitigate them and believes that the methodology is the best available for examining the relationship between Healthy Start and infant mortality and birth outcomes.

EFFECTS OF HEALTHY START ON PRENATAL CARE

One goal of Healthy Start was to link pregnant women and their infants to available services. During pregnancy, this effort focused on ensuring that women made prenatal care appointments, kept their appointments, and were satisfied with the quality of their prenatal care. Based on established medical guidelines, program staff encouraged women to start their care early, receive a recommended number of visits, receive necessary health screenings, have appropriate procedures performed, and receive health education.

No single measure of prenatal care adequacy can capture these multiple objectives and outcomes. Because of the importance placed on linking women to services, especially prenatal care, the outcomes analysis examined several measures of prenatal care: a summary index of the adequacy of prenatal care; measures of the adequacy of prenatal care initiation and adequacy

of the number of prenatal care visits; and various measures of content, satisfaction, and quality of care.

Kotelchuck Index of Adequacy of Prenatal Care Utilization

The Kotelchuck Index of the adequacy of prenatal care combines information on the initiation of prenatal care, number of visits received, and duration of pregnancy into a measure of the adequacy of prenatal care (Kotelchuck 1994). The index classifies prenatal care receipt into five categories: no care, inadequate care, intermediate care, adequate care, and adequate-plus care. This classification depends on the initiation of care (first trimester or later) and the number of recommended visits that were received, where the number of recommended visits depends on the duration of pregnancy. Although the index does not focus on the content of prenatal care, the Kotelchuck Index is regarded as the most comprehensive measure of the receipt of prenatal care available from vital records.

Across the 15 Healthy Start project areas, the percentage of women receiving adequate or better prenatal care ranged from less than 50 percent in Cleveland, the District of Columbia, New York City, and Northern Plains to more than 75 percent in Boston and Oakland (see Figure 5):

- # In 8 of the 15 project areas, the percentage of women who received adequate or better prenatal care was significantly higher than it would have been without Healthy Start (Figure 5).
- # The estimated effect of Healthy Start was strongest in Baltimore, Birmingham, Northern Plains, and Philadelphia, where the program was associated with an increase in the percentage of women receiving adequate or adequate-plus prenatal care by 4.0 to 6.4 percentage points.

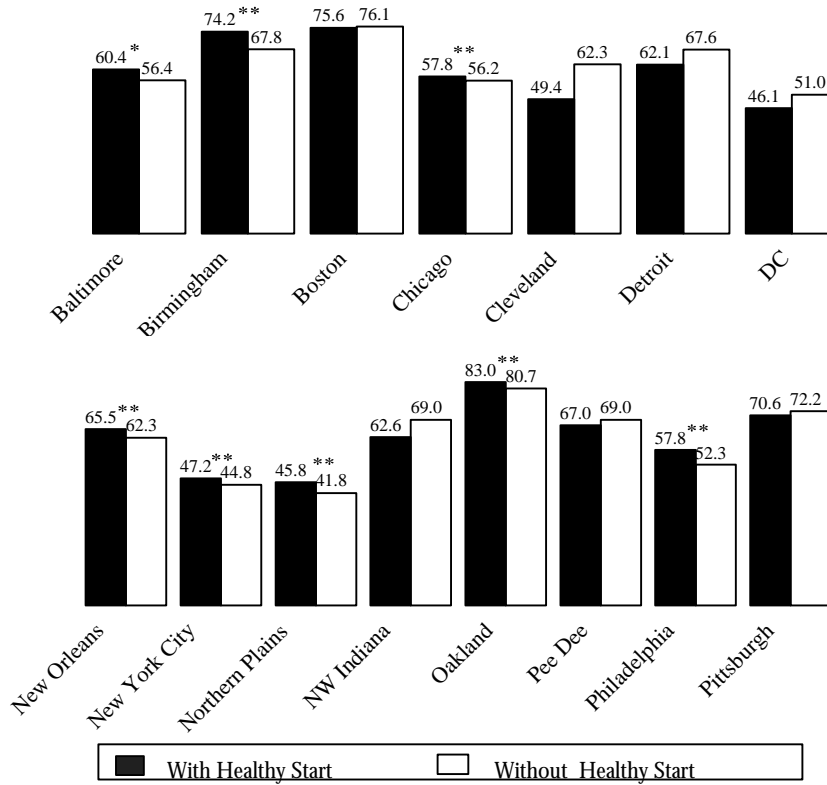
The Kotelchuck Index includes two components: (1) a subindex of initiation of prenatal care and, (2) a subindex of receipt of prenatal care services. These two measures indicate whether the improvements in adequacy of prenatal care discussed above are due to earlier initiation of care, a larger number of visits received, or both.

Kotelchuck Subindex of Initiation of Prenatal Care. The subindex of prenatal care initiation classifies initiation as adequate if the first prenatal care visit occurred by the fourth month of pregnancy. Looking at the effects of Healthy Start on the initiation of prenatal care, the principal findings are:

- # In 13 of the 15 project areas, the percentage of women with adequate initiation of care exceeded 70 percent, and was over 90 percent in Boston and Oakland (see Figure 6).
- # Healthy Start was associated with significant increases in the adequacy of prenatal care initiation in four project areas: Birmingham, New Orleans, New York City, and Philadelphia. The estimated effect of Healthy Start was highest in New Orleans, where the program was associated with an increase in the percentage of women receiving adequate or better initiation of prenatal care by almost four percentage points.

Figure 5**Effects of Healthy Start on the Adequacy of Prenatal Care Utilization**

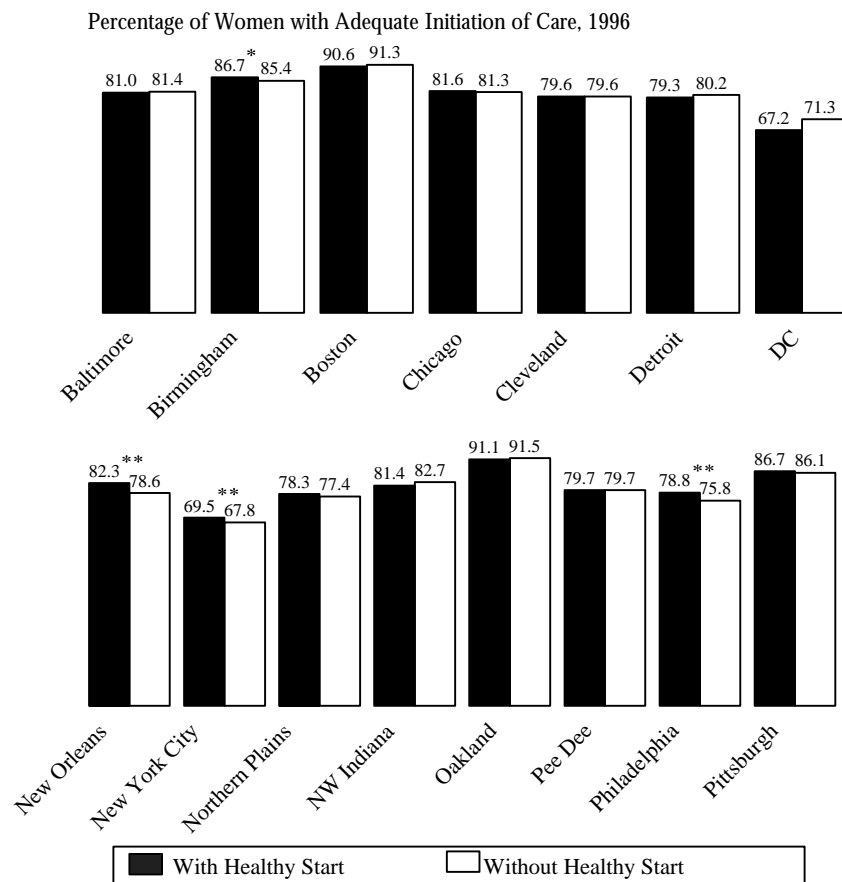
Percentage of Women Receiving Adequate or Better Prenatal Care
(Kotelchuck Index), 1996



Source: State vital statistics birth files, 1984-1996.

Note: All percentages are regression-adjusted.

(**): $p < .05(.01)$, one-tailed test.

Figure 6**Effects of Healthy Start on the Adequacy of Prenatal Care Initiation**

Source: State vital statistics birth files, 1984-1996.

Note: All percentages are regression-adjusted.

(**): $p < .05(.01)$, one-tailed test.

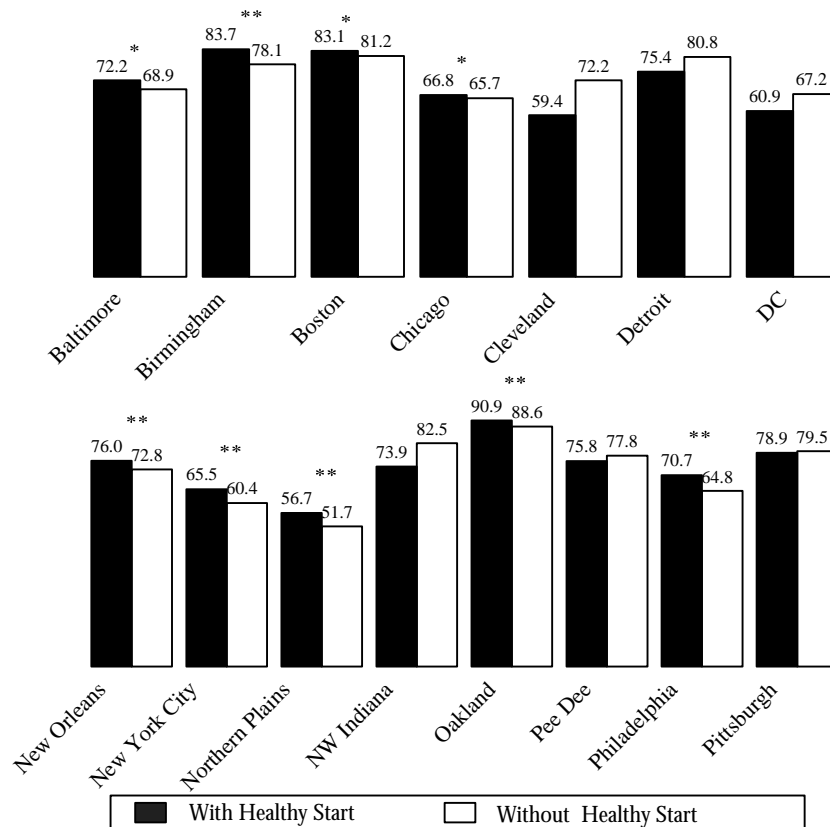
Kotelchuck Subindex of the Adequacy of Prenatal Care Visits. This subindex classifies prenatal care visits as adequate or better if the number of prenatal care visits received is at least 80 percent of recommended prenatal care visits:

- # In 9 of the 15 project areas, Healthy Start was associated with a significant increase in the percentage of women receiving an adequate or better number of prenatal care visits (Figure 7).
- # In Oakland Healthy Start, 90.9 percent of women received adequate or better number of prenatal care visits. In Baltimore, Birmingham, New Orleans, New York City, Northern Plains, and Philadelphia, Healthy Start was associated with an increase of three or more percentage points in the percentage of women whose receipt of services was adequate or better.

Figure 7

Effects of Healthy Start on the Adequacy of Prenatal Care Visits

Percentage of Women with an Adequate or Better Number of Prenatal Care Visits, 1996



Source: State vital statistics birth files, 1984-1996.

Note: All percentages are regression-adjusted.

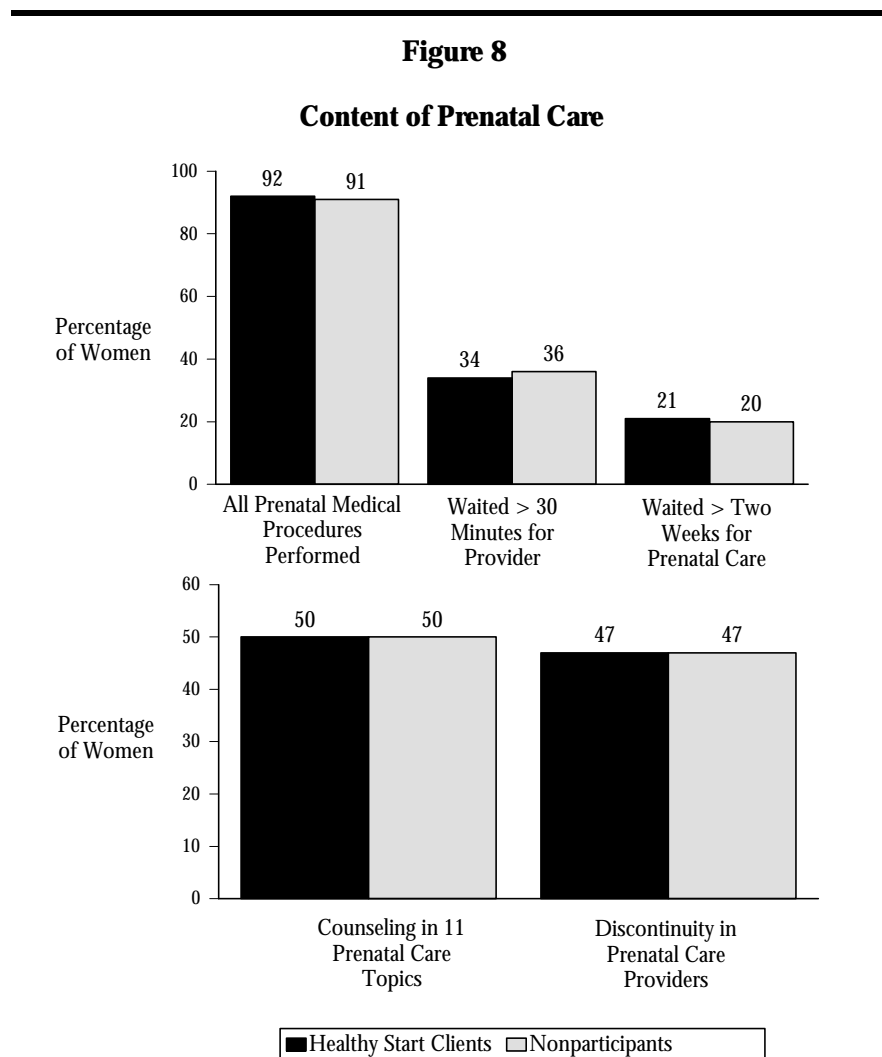
**): $p < .05(.01)$, one-tailed test.

Content of Prenatal Care

Healthy Start clients and nonparticipants did not differ significantly in their content of prenatal care (Figure 8). This similarity in the content of prenatal care suggests that any changes in the systems of care benefitted both Healthy Start clients and other women receiving prenatal care.

Specifically, data from the Healthy Start postpartum survey showed the following:

- # During their first two visits to a provider, over 90 percent of women living in Healthy Start project areas received six medical procedures: blood pressure screenings, urine and blood samples, height, weight, pregnancy history, and a pelvic exam (see Figure 8).



Source: Healthy Start Postpartum Survey, 1996.

Note: Estimates are regression-adjusted using data pooled across project areas. The differences between Healthy Start clients and nonparticipant are not statistically significant.

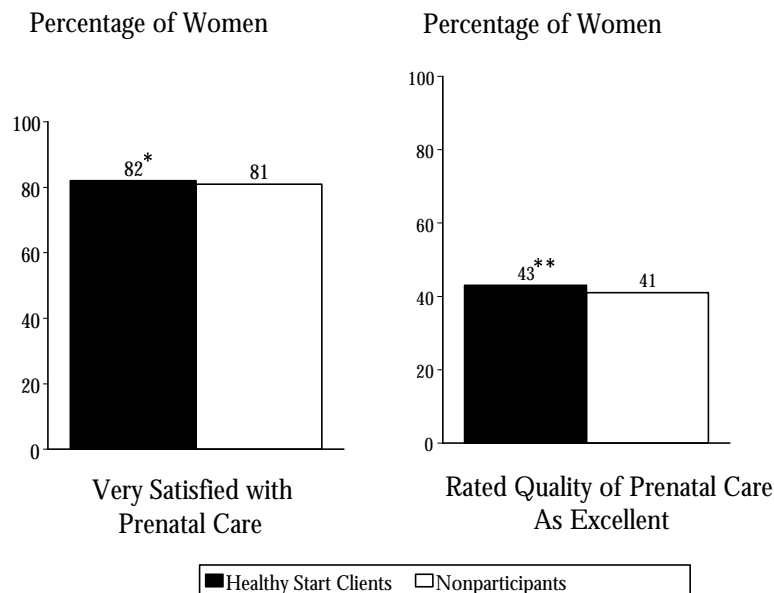
- # Waiting time, either to arrange for an appointment or to see the provider, was reasonable for women living in the Healthy Start project areas. Four-fifths of the pregnant women waited less than two weeks for a prenatal care visit, and almost two-thirds waited less than 30 minutes at their provider's office.
- # Half of the women living in the Healthy Start project areas received counseling on a set of 11 prenatal topics, which included weight gain, foods to eat, vitamins, exercising, child birth education classes, breastfeeding, not smoking, avoiding alcohol, avoiding drugs, ultrasound, and being tested for HIV/AIDS. A little less than half the women (47 percent), both Healthy Start clients and nonparticipants, reported a discontinuity in their prenatal care provider during pregnancy.

Satisfaction with Prenatal Care

More than 80 percent of women living in the Healthy Start project areas were very satisfied with their prenatal care (Figure 9). Healthy Start clients were more likely than other women to be very satisfied with their prenatal care (82 versus 81 percent) and to rate the quality of their care as excellent (43 versus 41 percent).

Figure 9

Effects of Healthy Start on Satisfaction with Care



Source: Healthy Start Postpartum Survey 1996.

Note: Estimates are regression-adjusted using data pooled across project areas.

**): $p < .05(.01)$

Table 12 looks more closely at the quality of care and provides insights into the perceived quality of prenatal care received:

- # Women living in the Healthy Start project areas overwhelmingly responded that the staff treated them with respect and that their providers seemed to know the latest in medical care.
- # Women also reported that they could make an appointment at a convenient time and that their providers were genuinely interested in them.
- # The concern cited most frequently by women living in the Healthy Start project areas was the thoroughness of care provided, with 21.3 percent of women indicating that they felt that their provider was not thorough enough.
- # Other concerns were feeling uncomfortable talking with the provider (13.6 percent) and the provider rushed through appointments (11.5 percent).

Table 12: Perceived Quality of Prenatal Care

Quality of Care Components	Percentage Agreeing
Positive Statements	
Staff treated you with respect	95.9
Provider knew the latest in medical care	94.3
You could make an appointment at a convenient time	89.0
Provider was genuinely interested in you	87.2
You could easily reach the provider with questions	80.5
Concerns Expressed	
Provider was not thorough enough	21.3
You were uncomfortable talking with the provider	13.6
Provider rushed through appointments	11.5
Provider ignored what you said	5.5

SOURCE: Healthy Start Postpartum Survey 1996.

In summary, Healthy Start was successful in increasing prenatal care utilization in many Healthy Start project areas. In eight project areas, the adequacy of prenatal care utilization was higher than it would have been without the program. In four project areas, more women started their care early because of Healthy Start. And in nine project areas, Healthy Start resulted in improvements in the adequacy of the number of prenatal care visits. The effects of Healthy Start were particularly strong in four project areas: Birmingham, New Orleans, New York, and

Philadelphia S which showed improvements in all three measures of prenatal care utilization attributed to Healthy Start. Satisfaction with prenatal care services was high in Healthy Start communities and women received a consistent set of medical procedures and screenings during pregnancy.

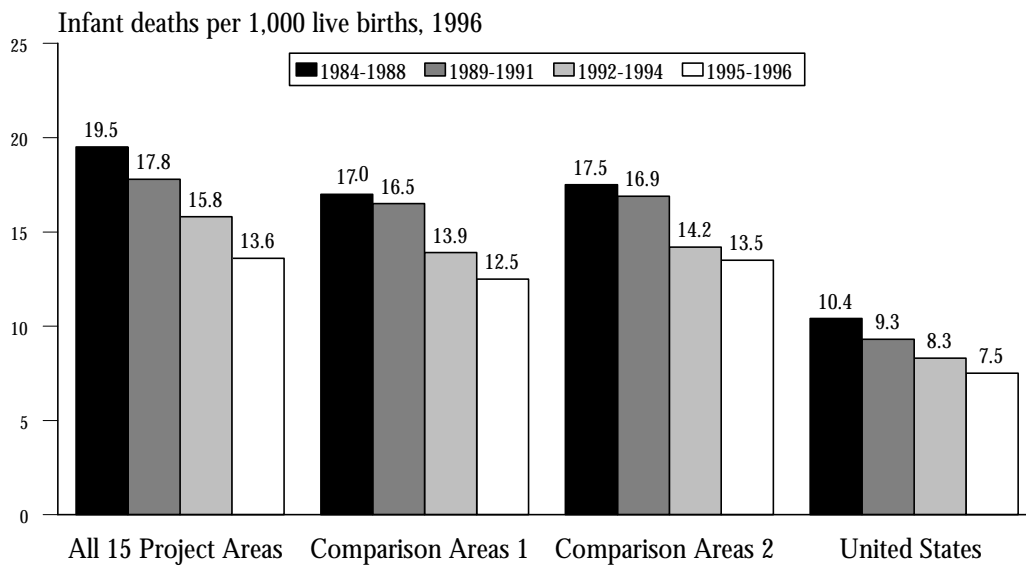
EFFECTS OF HEALTHY START ON INFANT MORTALITY

Infant mortality rates declined substantially between 1984 and 1996 in the Healthy Start project areas. Across all project areas, infant mortality declined from 19.5 infant deaths per 1,000 live births in the early pre-Healthy Start period (1984-1988) to 17.8 in the late pre-Healthy Start period (1989-1991) to 15.8 in the early years of the Healthy Start program (1992-1994), and, finally, to 13.6 in the full implementation period (1995-1996). This overall decline is 30.3 percent over the period 1984-1988 to 1995-1996 (Figure 10).

During this period, infant mortality also declined in the comparison areas and nationwide. The reduction in infant mortality in the Healthy Start project areas was slightly greater in magnitude than both the reduction nationwide and the reduction in the comparison areas. Taken together, these findings indicate nationwide reductions in infant mortality, with the reductions in the Healthy Start project areas being slightly larger than those observed in both similar community areas and the United States as a whole.

Figure 10

Infant Mortality Rates, Healthy Start Project Areas and Comparison Areas



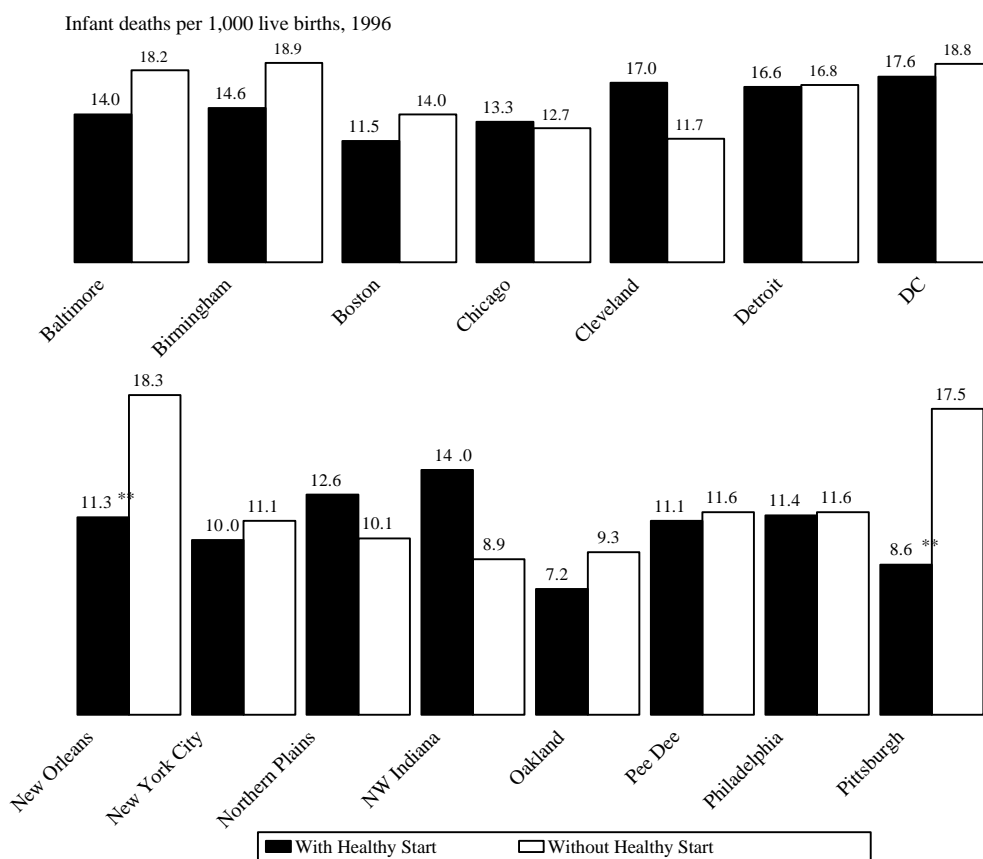
Source: State vital statistics birth and death files, 1984-1996.

The major findings on the effects of Healthy Start on infant mortality are:

- # In two project areas **S** New Orleans and Pittsburgh **S** Healthy Start was associated with a statistically significant reduction in infant mortality (Figure 11).
- # In New Orleans, the estimated reduction in infant mortality attributed to Healthy Start was 7 deaths per 1,000 live births (18.3 versus 11.3 infant deaths per 1,000 live births), a reduction of 38 percent.
- # In Pittsburgh, Healthy Start was associated with a reduction in infant mortality by 1996 from 17.5 to 8.6, a reduction of 51 percent.
- # In several other project areas **S** Baltimore, Birmingham, and Oakland **S** the reduction in infant mortality attributed to Healthy Start, though not statistically significant, was fairly large and close to statistical significance ($p < .10$).

Figure 11

Effects of Healthy Start on Infant Mortality

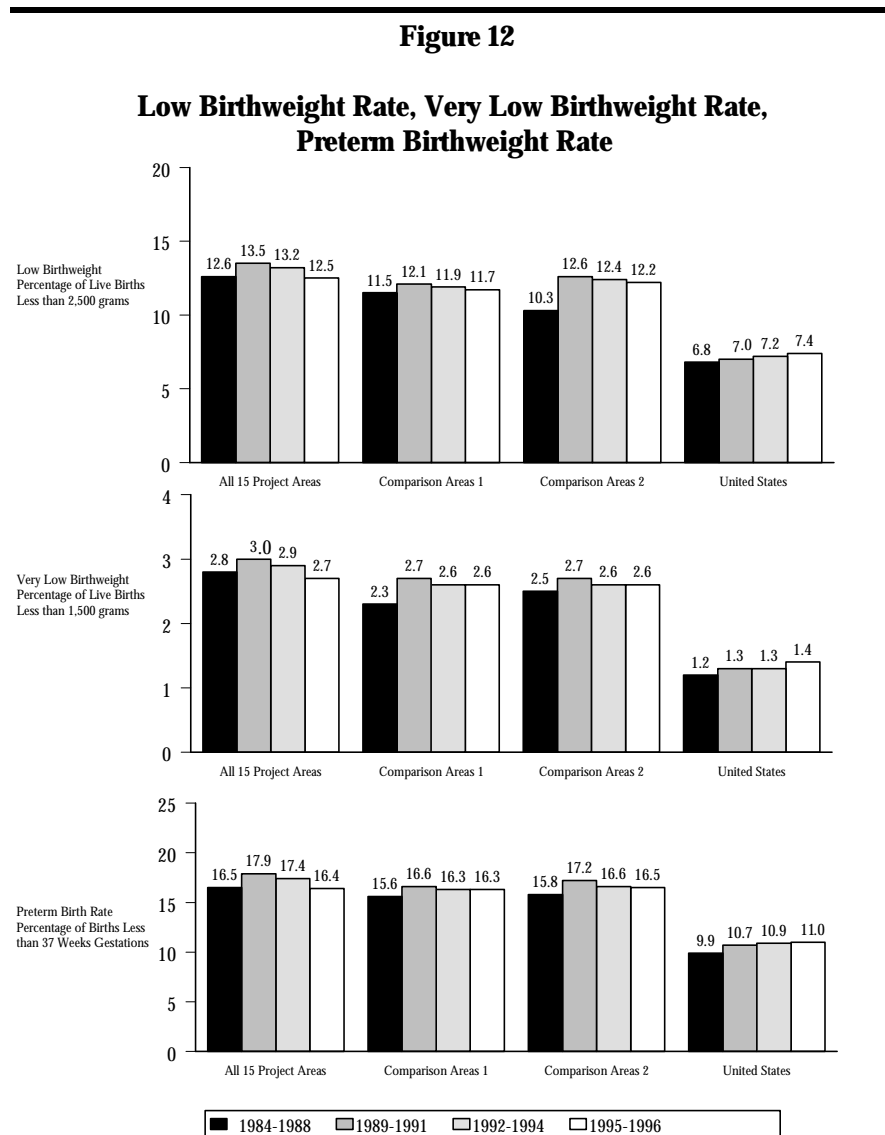


Source: State vital statistics birthfiles, 1984-1996.
 Note: All percentages are regression-adjusted.
 (**): $p < .05(01)$, one-tailed test.

PRETERM BIRTH RATE, LOW BIRTHWEIGHT RATE, AND VERY LOW BIRTHWEIGHT RATE

In contrast to nationwide declines in infant mortality over time, rates of low and very low birthweight and the rate of preterm birth changed very little over time (Figure 12). Across the 15 Healthy Start project areas, the percentages of births that were low birthweight and very low birthweight were almost unchanged from the baseline period of 1984-1988 to the full implementation period of 1995-1996: 12.6 percent versus 12.5 percent for low birthweight and 2.8 percent versus 2.7 percent for very low birthweight. Both sets of comparison areas, however, had increases in the percentage of births that were either low or very low birthweight. The second set of comparison areas, in particular, experienced an increase from 10.3 to 12.2 percent of births that were low birthweight. Nationwide, low birthweight rates increased from 6.8 percent in 1984-1988 to 7.4 percent in 1995-1996; the very low birthweight rate also increased from 1.2 percent in 1984-1988 to 1.4 percent in 1995-1996.

The rate of preterm birth also was relatively constant over time across the 15 Healthy Start project areas: 16.5 percent in the baseline period versus 16.4 percent in the full implementation period. In both sets of comparison areas and nationwide, however, the rate of preterm birth increased slightly. Together, these trends in infant mortality and birth outcomes suggest that the substantial decline in infant mortality over time occurred without significant improvements in related birth outcomes.



Source: State vital statistics birth files, 1984-1996.

The findings on the effects of Healthy Start on birth outcomes are:

- # In four project areas **S** Birmingham, New Orleans, Oakland, and Philadelphia **S** Healthy Start was associated with significant declines in the preterm birth rate (Table 13). This finding is particularly interesting in Oakland, because the preterm birth rate there was already the lowest of the 15 project areas.
- # Three project areas **S** Birmingham, Detroit, and the District of Columbia **S** had significant reductions in the rate of low birthweight resulting from Healthy Start.
- # In Birmingham, Boston, and Pittsburgh, Healthy Start was associated with significantly lower rates of very low birthweight.

Table 13: Effects of Healthy Start on Preterm, Low, and Very Low Birthweight Rates, 1996

Project Area	Preterm Birth Rate, 1996 (Percentage of Births)		Low Birthweight Rate, 1996 (Percentage of Births)		Very Low Birthweight Rate, 1996 (Percentage of Births)	
	With Healthy Start	Without Healthy Start	With Healthy Start	Without Healthy Start	With Healthy Start	Without Healthy Start
Baltimore	22.4	22.5	17.8	17.6	3.5	3.8
Birmingham	17.6**	20.5	12.3**	14.9	3.2**	4.6
Boston	19.6	19.4	11.8	12.5	2.9*	3.6
Chicago	18.1	18.3	13.0	13.1	2.4	2.5
Cleveland	17.6	16.2	14.5	12.3	3.4	2.1
Detroit	18.4	18.6	14.2**	15.8	3.0	3.4
District of Columbia	20.9	20.5	16.2*	17.9	4.4	4.6
New Orleans	19.4*	21.3	14.2	15.1	3.1	3.4
New York City	14.5	14.5	11.6	11.6	2.5	2.6
Northern Plains	12.2	12.6	6.3	6.5	1.4	1.1
Northwest Indiana	14.2	15.0	10.4	9.5	2.1	1.9
Oakland	11.3**	12.6	9.4	9.2	1.5	1.5
Pee Dee, South Carolina	14.5	13.8	11.7	11.2	2.4	2.2
Philadelphia	16.7**	18.1	13.5	14.0	3.1	2.9
Pittsburgh	15.5	14.2	11.9	11.9	2.3*	2.8

SOURCE: State vital statistics birth and death files, 1984-1996.

*(**): $p < .05$ (.01), one-tailed test.

SUMMARY AND DISCUSSION

The outcomes analysis of the national evaluation of Healthy Start examined a broad range of outcomes, including prenatal care adequacy, preterm birth rate, low- and very-low birthweight rate, and infant mortality. The analysis results indicate improvements in several birth outcomes across the 15 original project areas and reductions in infant mortality in 2 project areas. As summarized in Table 14, the principal results are the following:

- C *Prenatal Care Utilization.* Healthy Start was associated with significant improvements in many of the measures of prenatal care utilization.
 - In 8 of the 15 project areas, Healthy Start was associated with improved adequacy of prenatal care utilization: Baltimore, Birmingham, Chicago, New Orleans, New York City, Northern Plains, Oakland, and Philadelphia.
 - In 4 of the 15 project areas, Healthy Start was associated with increases in the adequacy of prenatal care initiation: Birmingham, New Orleans, New York City, and Philadelphia.
 - In 9 of the 15 project areas, Healthy Start was associated with improved adequacy of the number of prenatal care visits: Baltimore, Birmingham, Boston, Chicago, New Orleans, New York City, Northern Plains, Oakland, and Philadelphia.
- C *Preterm Birth Rate.* In 4 project areas, Healthy Start was associated with a lower preterm birth rate: Birmingham, New Orleans, Oakland, and Philadelphia.
- C *Low and Very Low Birthweight Rates.* Three project areas **S** Birmingham, Detroit, and the District of Columbia **S** had significant reductions in the rate of low birthweight resulting from Healthy Start. In Birmingham, Boston, and Pittsburgh, Healthy Start was related to reductions in the rate of very low birthweight.
- C *Infant Mortality Rate.* Infant mortality rates declined significantly in the Healthy Start project areas between the baseline period of 1984 through 1988 and 1996. Infant mortality rates declined by roughly the same magnitude in similar comparison areas and in the nation as a whole. In two project areas, New Orleans and Pittsburgh, Healthy Start was associated with significant reductions in infant mortality.

Three project areas **S** Birmingham, New Orleans, and Pittsburgh **S** had significant improvements in several birth outcomes and fairly large reductions in infant mortality attributed to Healthy Start. Birmingham had the most consistent set of findings. Compared with its matched comparison areas, Birmingham had statistically significant improvements in the adequacy of prenatal care utilization, statistically significant reductions in the preterm birth rate and rates of low and very low birthweight, and a large (but not quite statistically) significant decline in the infant mortality rate. New Orleans also showed statistically significant effects of Healthy Start: improvements in prenatal care adequacy, including improvements in every measure of prenatal care utilization and adequacy; a decline in the preterm birth rate; and a

Table 14: Summary of Outcomes Analysis Results

Project Area	Adequacy of Prenatal Care			Preterm Birth Rate	Low Birthweight Rate	Very-Low Birthweight Rate	Infant Mortality Rate
	Utilization	Initiation	Visits				
Baltimore	X		X				
Birmingham	X	X	X	X	X	X	
Boston			X			X	
Chicago	X		X				
Cleveland							
Detroit					X		
District of Columbia					X		
New Orleans	X	X	X	X			X
New York City	X	X	X				
Northern Plains	X		X				
Northwest Indiana							
Oakland	X		X	X			
Pee Dee							
Philadelphia	X	X	X	X			
Pittsburgh						X	X

X denotes a statistically significant difference in outcomes with and without Healthy Start for a significance level of 5 percent or lower, one-tailed test.

reduction in the infant mortality rate. In Pittsburgh, Healthy Start was associated with a significant reduction in both the very low birthweight rate and infant mortality rate.

Two additional project areas **S** Baltimore and Oakland **S** also had significant improvements in birth outcomes and reductions in infant mortality that were close to statistical significance. In Baltimore, Healthy Start was related to improvements in the adequacy of prenatal care utilization and a large, but not statistically significant, decline in the infant mortality rate. The Healthy Start program in Oakland was related to improvements in the adequacy of prenatal care utilization and a reduction in the preterm birth rate. In addition, by the end of the demonstration period, infant mortality in the Oakland project area was very low and close to the national average.

Philadelphia Healthy Start also demonstrated improvements in birth outcomes attributed to Healthy Start. Specifically, Healthy Start was associated with significant improvements in all measures of prenatal care utilization and a significant reduction in the preterm birth rate.

What accounts for these results? Several aspects of these more successful Healthy Start programs are important to highlight in interpreting these outcomes.

Baltimore

Baltimore Healthy Start was associated with improvements in the adequacy of prenatal care utilization and a considerable, but not statistically significant, decline in the infant mortality rate. Several factors are important to note about the Baltimore program. First, Baltimore ranked the highest of all programs on program organization and administration. The city health department was the grantee, but it contracted with a nonprofit agency to implement and manage the program. Baltimore also ranked highly on service coordination, particularly the integration of the program with clinical and social services, and on service implementation, most notably on whether the outreach and case management programs were well established and implemented consistently across providers. Baltimore also had the highest enrollment rate of the Healthy Start target population.

Community involvement, primarily through the employment of lay community workers, was a cornerstone of the Baltimore Healthy Start model. Interestingly, Baltimore (along with Birmingham) ranked among the lowest of the project areas on the consortium. While a central consortium developed and met throughout the demonstration period, its role was only advisory, and participation by key political figures, providers, and consumers was low.

Birmingham

Birmingham Healthy Start showed the most consistent set of findings. Compared with its matched comparison areas, Birmingham had statistically significant improvements in the adequacy of prenatal care; statistically significant reductions in the preterm birth rate, and rates of low and very low birthweight; and a fairly large (but not statistically significant) reduction in infant mortality.

Birmingham Healthy Start was closely linked with the local health department, resulting in enhanced links to the existing clinical care system. Birmingham also developed the strongest management information system, which was capable of linking clients to services received. Additionally, the University of Alabama, Birmingham, operated the Low Birthweight Patient Outcome Research Team (PORT) program during this period. This included interventions to improve birth outcomes in the Healthy Start project area. On the other hand, staff turnover was high. Site visitors ranked Birmingham the lowest of the project areas on several factors, including the level of political support, the consortium, and program organization and administration.

New Orleans

The Healthy Start program in New Orleans, called Great Expectations, was associated with significant improvement in prenatal care adequacy, a decline in the preterm birth rate, and reduced infant mortality. The decline in infant mortality was most pronounced in 1996, when the regression-adjusted infant mortality rate in New Orleans fell to 11.3, compared with fairly large increases in both comparison areas.

Several aspects of the Healthy Start program in New Orleans may explain its success in improving outcomes. First, Healthy Start provided an important catalyst in New Orleans to improve the primary care delivery system in the community. By funding five community clinics, Healthy Start filled a void in the community health care system and alerted the medical community to issues surrounding access to primary care. In addition, through what the program called local godparents *S* *NaNans* and *Parrains S* the program implemented a strong personal outreach program that enrolled high-risk women in the community-based case management programs. Site visitors perceived *Great Expectations* as successful at service coordination and rated the program highly on its components *S* integration of clinical and social services, co-location with other programs, and acquiring and using materials from other programs operating in the project area.

Second, although the New Orleans Health Department was the Healthy Start grantee, the health department contracted with a nonprofit agency to implement and manage the program. New Orleans ranked highly on program organization and administration.

Third, New Orleans was strong on community involvement in Healthy Start. Through both a central consortium and multiple local consortia, the program worked intensively to involve local residents. The local consortia were major participants in the central consortium; each local consortium had a representative to the Steering Committee. Local consortia also had a role in reviewing the proposals submitted to *Great Expectations* for Healthy Start funding.

Finally, the New Orleans project area experienced an increase in the percentage of deliveries in hospitals with neonatal intensive care units (NICU) over the course of the Healthy Start demonstration period, especially in contrast to its comparison areas and to the other Healthy Start project areas. Specifically, the percentage of deliveries in NICU hospitals in the New Orleans project area increased from 42 percent in the 1989-1991 pre-intervention period to 63 percent in 1994-1995, while the percentages were stable over time in the comparison areas and in all other project areas (Richardson et al. 2000). Earlier research shows significantly higher neonatal survival for very low birthweight infants born in NICU hospitals, compared with hospitals without NICUs (Paneth et al. 1982; and Gortmaker et al. 1985).

Oakland

The Healthy Start program in Oakland was related to improvements in the adequacy of prenatal care utilization and reduction in the preterm birth rate. In fact, the Oakland area had the highest percentage of women receiving adequate or better prenatal care. In addition, infant mortality in Oakland is very low and close to the national average. Healthy Start was associated with an estimated 22.6 percent decline in infant mortality, although this estimate was not statistically significant.

As was true of many programs with improved outcomes, Oakland Healthy Start was strong on program organization and administration. Political support for the program was high, and the staffing was relatively stable during the demonstration phase.

The main Healthy Start intervention was the establishment of the Family Life Resource Centers (FLRCs), based on a “one-stop shopping” model, in each of the program’s target areas. Because of the links of the FLRCs with the existing clinical care system, Oakland Healthy Start ranked very highly on service coordination.

Philadelphia

The Philadelphia Healthy Start program was related to improvements in the adequacy of prenatal care utilization and a reduction in the preterm birth rate. In addition, the improved adequacy of prenatal care utilization reflected both earlier initiation of prenatal care and an increase in the number of prenatal care visits.

The underlying approach of the Philadelphia Healthy Start program was to create a system-wide intervention to enhance the capacity of the existing maternal and child health system. The program contracted with 65 clinical and community-based providers to deliver services to clients, which was the largest of all the Healthy Start programs.

The program was organized into six service intervention models: clinical service enhancement; lay home visiting; outreach; social support services; health education; and adolescent services. Contracts with five hospitals helped to identify pregnant women in need of services. The program also established “Health Corners” as community outreach sites to enroll women in the program, refer them to services, and provide health education. The contract monitoring process was well developed and became an early model for other Healthy Start project areas.

The scope of the program was broad, both in terms of its target area and number of women served. The project area was among the largest of the Healthy Start project areas, and the volume of clients also was among the highest, with over 7,000 women and children enrolled in fiscal year 1996 alone. Philadelphia Healthy Start also ranked highly on the integration of clinical and social services.

Pittsburgh

Pittsburgh Healthy Start was associated with a significant reduction in the very low birthweight rate and in the infant mortality rate. The decline in infant mortality attributed to the program is large. Pittsburgh is the only program that achieved the 50 percent goal of the demonstration.

Pittsburgh Healthy Start shares three characteristics with the program implemented in New Orleans. First, the program had a strong community-based model, in which local outreach and case management teams focused on their own neighborhoods. Pittsburgh also ranked highly on service coordination; in particular, the case management programs were closely integrated with the existing clinical and social service system. Second, the Allegheny Health Department was the grantee, but it subcontracted program management to a nonprofit agency, an arrangement that facilitated staff hiring and retention. Site visitors ranked Pittsburgh among the highest of the project areas on program organization and administration and on whether the outreach and case management programs were well established and consistently implemented

across providers. Finally, the program had strong community involvement and a consortium with especially strong leadership. Healthy Start was successful at involving consumers in the consortium, and the consortium operated as a forum for receiving community concerns and exchanging information.

One other aspect of the Pittsburgh Healthy Start program is important to note in interpreting the study findings. Site visitors from the national evaluation team concluded that staff turnover was one factor that hindered implementation of Healthy Start. While the Pittsburgh program had some turnover of key staff at the outset, it currently is the only program that has the original project director.

Characteristics of Successful Healthy Start Programs

When looking carefully at the characteristics of the more successful programs, several conclusions emerge:

- # *Strong program organization and administration, with stable program leadership, was associated with better program implementation and improved outcomes.* Four of the six programs with the best outcomes **S** Baltimore, New Orleans, Oakland, and Pittsburgh **S** were ranked highly on program organization and administration. Three of these programs relied on a private, nonprofit agency to implement and manage the program, and all four had strong project directors during the demonstration period.
- # *Programs that focused on service coordination, with close links to the existing clinical care system, were more successful than others.* A major focus of Healthy Start was to link women and their families to needed services. All of the more successful programs ranked very highly on service coordination.
- # *Community involvement through the employment of community residents was associated with improved outcomes in some but not all programs.* Baltimore, Birmingham, New Orleans, and Pittsburgh implemented programs based on significant employment of community residents. So also did numerous other programs, without the associated improvements in infant mortality and related birth outcomes. Again, the main factor distinguishing these programs is the strength of program administration and organization. That is, those programs with both strong program administration and employment of community residents had better outcomes than those with only one or the other.

CHAPTER VI

CONCLUSIONS AND LESSONS LEARNED

Healthy Start was a community-based demonstration program to reduce infant mortality and improve birth outcomes in communities with high rates of infant death. Healthy Start grantees had considerable latitude in designing and implementing their programs, resulting in both direct service delivery and system changes designed to improve the service delivery network for low-income women and their families.

Much has been learned from the original 15 Healthy Start programs. The evaluation findings and lessons learned are important for considering how to design and implement similar community-based interventions, how to modify existing Healthy Start programs, and what the potential impacts are on infant mortality and related birth outcomes.

PRINCIPAL EVALUATION FINDINGS

Over the past six years, a comprehensive evaluation of the 15 original Healthy Start demonstration programs has been conducted. This evaluation included both a complete process and outcomes analysis and several reports with numerous findings (see Appendix A). The following summary of the principal findings is useful for review and for consideration of the key lessons learned from the demonstration and its evaluation.

- # All programs were successful at developing and implementing a comprehensive Healthy Start plan during the demonstration period. Most programs were not fully operational until calendar year 1995.
- # Case management was the most common Healthy Start intervention. Health education also was an important intervention, provided either as part of the case management process or through direct service delivery.
- # Important, specific findings about Healthy Start case management were:
 - Outreach, advocacy, and referrals were the strongest components of Healthy Start case management.

- Healthy Start case management programs relied heavily on lay community workers. This model of case management is believed to have helped identify and enroll higher-risk women.
- Caseloads were high, particularly given the high-risk nature of the population, the widespread employment of lay workers, and the intensive, home visiting-based models implemented.
- # Healthy Start was successful at identifying and enrolling high-risk women. At the same time, the programs had a difficult time maintaining contact and engaging these clients on a long-term basis. Healthy Start case records showed numerous, unsuccessful attempts to contact clients, either by telephone or by home visits.
- # Improvements in outcomes occurred during the demonstration period. Eight of the 15 project areas showed improvement in the adequacy of prenatal care utilization; two project areas had significant reductions in infant mortality; four project areas had declines in the preterm birth rate; and three project areas had reductions in the rate of low birthweight and the rate of very low birthweight.
- # Despite considerable investment, programs were unsuccessful in developing a management information system that would allow for the ongoing tracking of service receipt by clients. Client-level data were of poor quality and were of limited use for program monitoring and for evaluation purposes.

LESSONS LEARNED

By the end of the demonstration phase of Healthy Start, some key lessons had emerged about factors influencing the implementation and effects of the program. These lessons fall into the following categories:

- # Program organization and administration
- # Community involvement
- # Service delivery
- # System changes

Program Administration and Organization. As with any large, complex program, the successful organization and administration of Healthy Start was important. The extent to which programs were able to recruit and retain a strong staff (especially senior staff), develop and implement effective administrative procedures, and monitor the work of contractors made the difference between successful and less-than-successful implementation.

- < **An efficient administrative structure for the timely hiring of program staff and implementation of the Healthy Start interventions was a combination of public and private nonprofit administration.**

Four programs (Baltimore, Boston, New Orleans, and Pittsburgh) developed a nonprofit subsidiary of city or county government to administer Healthy Start, and the grantee in New York City was an existing nonprofit with strong ties to city government. These arrangements had several advantages. The administrative structures in local government for accounting and data processing did not have to be developed from scratch, and the preexisting organizational structure could be a source of interim program staff. In addition, because a nonprofit organization is independent of local personnel and contracting regulations, it had more flexibility to develop its Healthy Start program quickly, without having to follow a time-consuming hiring and approval process.

On the other hand, a primary role for the health department was important to sustaining Healthy Start beyond the federal grant-funding period. Through the influence of health department employees who maintained contact with or were employed by Healthy Start, program features were more likely to become an integral part of future health department activities, either as fully funded, free-standing activities or as part of existing programs.

The importance of strong program organization and administration is underscored by the findings from the outcomes analysis. Four of the six project areas showing significant improvements in birth outcomes were strong on this dimension; three used the administrative structure of a public agency as the grantee and a private, nonprofit agency to administer and manage the program.

- < **Timely hiring of strong senior staff and stability of program staff were key to successful implementation.**

Leading a Healthy Start program with an annual multimillion-dollar budget proved to be a challenging job requiring administrative ability (including skills in personnel, accounting, and data systems), experience in community relations, political acumen, and a knowledge of programs related to infant mortality. It is not surprising that leadership was important to success; this would be true of any large endeavor. While it was ideal to have continuity of senior staff throughout the life of the program, skilled staff who were recruited later also contributed significantly. In addition, it proved advantageous to select staff familiar with the Healthy Start community and of the same ethnic group as the majority of community residents.

Seven programs reported difficulty in hiring and retaining staff. Program staff pointed to bureaucratic delays in the hiring process, usually imposed by the grantee's agency. The most important staff position was the project director, defined as the person with day-to-day responsibility for administering the program. A project director who provided effective leadership to the staff was critical to implementation success. Site visitors rated most Healthy Start project directors highly.

Six programs experienced staff turnover which interfered with program implementation. When turnover occurred, especially in the more senior positions, it had a negative impact on the timing of implementation and on other aspects of program administration.

The importance of staff stability is clear when looking at those project areas with improved birth outcomes. Four of the six more successful programs ranked highly on having a stable Healthy Start staff. Currently, Pittsburgh Healthy Start **S** the one project area with an estimated 50 percent reduction in infant mortality **S** is one of only two project areas of the original 15 with the same project director.

Community Involvement. Healthy Start had a strong emphasis on community involvement. All programs took this mandate seriously, but all found it difficult and challenging. Only one community involvement strategy was mandated by HRSA, that of community consortia with required consumer membership. However, this mandate was interpreted differently from program to program. Some programs did not view the consortia as an important source of community input or governance, while others treated the consortia as major components of the intervention.

< **The community consortia were time-consuming and labor-intensive, and often resulted in slower implementation and community tensions.**

Programs with active consortia devoted much energy and time to convening and sustaining them. At times, the community consortia mandate was interpreted very differently by those involved, which led to substantial staff and community frustration. Conflict arose in a small number of programs when community members learned that “community-based decision making” did not, for example, mean that the consortia had the power to control the program budget. (When such conflict was severe, outside consultants proved to be effective in improving consortia/staff relationships.) To avoid some of the discord and related implementation delays experienced by some Healthy Start programs and communities, future community-based demonstration programs requiring consortia need to define clearly the purpose and roles of that organization before the demonstration begins.

Moreover, while two of the Healthy Start programs that ranked highly on the consortia showed improved birth outcomes, strong consortia did not appear directly related to improved outcomes. Many other programs also ranked highly on the consortia but did not have improved outcomes, and two programs with improved birth outcomes were ranked low on consortia development.

< **Consumer involvement in the central consortia was weak across all programs, despite a variety of innovative strategies to involve consumers.**

All programs wanted consumers to be involved in their consortia. While programs adopted a variety of strategies to involve consumers **S** such as transportation assistance, child care, and flexibility in the place and time of meetings **S** their involvement remained weak. Many central consortia included the groups and individuals that prepared the original grant proposal, several

of whom were state and local officials or provider representatives. Program staff reported that consumers felt intimidated by the professional composition of consortia and by formal consortia structures and committees.

The most promising strategies that addressed this weakness were smaller, less formal committees that met in the community. Even in these “local consortia,” however, community-based providers receiving Healthy Start funds were more active than consumers. In addition, the effort and time required to organize these groups was a strain on program staff. Still, site visitors judged local consortia to be the most promising avenue for consumer and other forms of grassroots community involvement in Healthy Start.

< Provider involvement in the consortia was useful for developing service networks.

While Healthy Start programs did not establish formal, closed provider networks, they did use various mechanisms to create a forum in which many different providers could interact, thus increasing the exchange of information and facilitating appropriate referrals. This was accomplished primarily through consortia and the activities of their committees.

Providers were often influential in developing the original Healthy Start proposal and may have already had a defined role in service delivery as part of that process. Other providers may have “come to the table” hoping for a new or expanded role in the program. This financial incentive was only one reason for involvement (others included commitment to the health issues involved and to improving systems of care), and overall provider involvement was highly beneficial to Healthy Start.

< Employment strategies, including hiring local residents and contracting with community-based organizations, broadened community involvement and interest in Healthy Start.

Programs found that infant mortality was not an important issue for most community residents, but that economic issues stimulated community interest and involvement. Employing residents of Healthy Start communities to deliver some form of services (usually outreach and case management services) was a common strategy to increase community involvement in all Healthy Start programs. Some programs have played a critical role in job training and job creation in their communities. This is true of Baltimore, where the area targeted most intensively by Healthy Start was small and the number of community residents employed was large. Heavy employment of community residents also holds risks, since a large number of employees might not be able to find other jobs if reduced federal funding for Healthy Start causes cutbacks.

An alternative to employing residents directly as a means of involving the community was to contract with community-based providers for services, since such organizations were themselves likely to employ community residents. Selecting providers was often fully or partly delegated to local consortia, which gave these groups a substantial and useful role. To the extent that communities supported businesses that would continue beyond grant funding, this strategy was potentially more sustainable than direct employment of community residents.

Service Delivery. The Healthy Start demonstration revealed several important lessons about developing new services and enhancing the service delivery systems in high-risk communities.

< **Healthy Start programs filled important gaps in services reaching beyond the traditional scope of clinical care.**

The services provided by Healthy Start included outreach, case management, and support services such as transportation and nutrition education. These support services are generally not provided in traditional clinic settings, despite their value in filling gaps in the service delivery system and creating a seamless, user-friendly system of care for higher-risk women and children. As managed care becomes a dominant component of health care systems, these facilitating and coordinating services may receive greater attention, and much can be learned from the Healthy Start experience about how to deliver such services and what they will cost.

< **Including lay workers as members of case management teams is a promising approach to identifying high-risk women and bringing them into care.**

Case management, the central service component implemented by all Healthy Start programs, was intended to identify, reach, and engage high-risk women in the health care service delivery system. Given the variation in how the programs were defined and in the intensity with which services were implemented, the picture of case management in Healthy Start reveals a wide range of personnel types, caseloads, and activities.

Classifying models of case management and implementing various systems, using standardized models, may be possible in the newer Healthy Start programs. The lay worker model holds great promise for providing services that are accessible and satisfying to mothers served by Healthy Start. This model appears to work best when it (1) is implemented by teams with low ratios of lay workers to professional workers, (2) incorporates intensive and ongoing training and mentoring, and (3) keeps caseloads low for the lay workers.

System Changes. From its inception, the Healthy Start program emphasized changing systems of care for low-income women and their families so they would have access to needed services. In most Healthy Start project areas, the needs assessments conducted during the first year of the demonstration period indicated that the supply of clinical services was adequate but that the greatest need was to coordinate available services in an appropriate, effective manner.

< **Service coordination was a major focus of most Healthy Start programs. In general, those programs with improved outcomes were those with the closest links to the existing clinical care system.**

Healthy Start programs developed and evolved within an existing service delivery environment. Most programs believed that coordinating existing services was more important than creating new services; as a result, programs used funds specifically to enhance the existing service delivery system. Case management emerged as the main service delivery intervention for achieving service coordination. Other program components S public information campaigns, the consortium, management information systems, and the infant mortality review S were also intended to improve systems of care.

REFERENCES

- Baltay, Michelle, Marie McCormick, and Paul Wise. "Evaluation of the Fetal and Infant Mortality Review (FIMR) Programs in the Healthy Start Programs." Boston, MA: Harvard School of Public Health, July 1997.
- Devaney, Barbara, Barbara Foot, and Dexter Chu. "Case Management in Healthy Start." Princeton, NJ: Mathematica Policy Research, March 1999.
- Division of Healthy Start. "Healthy Start." U.S. Department of Health and Human Services, Health Resources and Services Administration, February 1994.
- Gortmaker, S., A.C. Sobol, D.K. Clark, and A. Geronimus. "The Survival of Very Low-Birth Weight Infants by Level of Hospital of Birth: A Population Study of Perinatal System in Four States." *American Journal of Obstetrics and Gynecology*, vol. 152, no. 5, July 1, 1985, pp. 517-524.
- Harrington, Mary, Barbara Foot, and Elizabeth Closter. "Using Health Education to Reduce Infant Mortality: The Healthy Start Experience." Washington, DC: Mathematica Policy Research, Inc., September 2, 1998.
- Howell, Embry, Beth Zimmerman, and Elizabeth Closter. "Infant Mortality Prevention in American Indian Communities: Northern Plains Healthy Start." Washington, DC: Mathematica Policy Research, January 1999.
- Howell, Embry, Barbara Devaney, Barbara Foot, Jane Griffin, Mary Harrington, Ian Hill, Marie McCormick, Renee Schwalberg, Amy Zambrowski, and Beth Zimmerman. "Implementing a Community-Based Initiative: The Early Years of Healthy Start." Washington, DC: Mathematica Policy Research, Inc., November 1994.
- Howell, Embry M., Barbara Devaney, Marie McCormick, and Karen Thiel Raykovich. "Back to the Future: Community Involvement in the Healthy Start Program." *Journal of Health Politics, Policy and Law*, vol 23, no. 2, April 1998, pp. 291-317.
- Howell, Embry M., Barbara Devaney, Barbara Foot, Mary Harrington, Melissa Schettini, Marie McCormick, Ian Hill, Renee Schwalberg, and Beth Zimmerman. "The Implementation of Healthy Start: Lessons for the Future." Washington, DC: Mathematica Policy Research, Inc., November 1997.
- Kotelchuck, Milton. "An Evaluation of the Kessner Adequacy Prenatal Care Index and a Proposed Adequacy of Prenatal Care Utilization Index." *American Journal of Public Health*, vol. 84, 1994, pp. 1414-1420.
- Lewin-ICF, Inc. and MDS Associates, Inc. "Evaluation Design: Healthy Start, a Presidential Initiative to Reduce Infant Mortality." August 1992.

-
- McCann, Thurma, Bernice Young, Donna Hutten, Angela Hayes, and Beverly Wright. *The Healthy Start Initiative: A Community-Driven Approach to Infant Mortality Reduction* Vol. IV. *Community Outreach*. Arlington, VA: National Center for Education in Maternal and Child Health, 1996.
- Moreno, Lorenzo, Barbara Devaney, Dexter Chu, and Melissa Seeley. "Effect of Healthy Start on Infant Mortality and Birth Outcomes." Princeton, NJ: Mathematica Policy Research, Inc., July 2000.
- National Center for Health Statistics. *Health, United States, 1998 with Socioeconomic Status Chartbook*. Hyattsville, MD: U.S.P.H.S., 1998.
- Paneth, N., J.L. Kiely, S. Wallenstein, M. Marcus, J. Parker, and M. Susser. "Newborn Intensive Care and Neonatal Mortality in Low-birth Weight Infants: A Population Study." *New England Journal of Medicine*, vol. 307, no. 3, July 15, 1982, pp. 149-155.
- Richardson, Douglas, Marie C. McCormick, Embry Howell, Barbara Devaney, and Lorenzo Moreno. "Level of Care Analyses for the National Evaluation of the Healthy Start Program." Washington, DC: Mathematica Policy Research, Inc., March 2000.
- Simon, Della, and Karen Thiel Raykovich. "The Role of Outreach Workers in the Healthy Start Program." Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration, November 1995.
- Ventura, Stephanie J., Robert N. Anderson, Joyce A. Martin, and Betty Smith. "Birth and Infant Deaths: Preliminary Data for 1997." *National Vital Statistics Reports*, vol. 47, no. 4, October 7, 1998a.
- Ventura, Stephanie, Joyce A. Martin, Sally C. Curtin, and T.J. Mathews. "Report on Final Natality Statistics, 1996." *Monthly Vital Statistics Report*, vol. 46, no. 11, supplement, June 30, 1998b.

APPENDIX A

REPORTS FROM THE NATIONAL EVALUATION OF HEALTHY START

Other Project Reports from the National Evaluation of Healthy Start

- Howell, Embry, Barbara Devaney, Barbara Foot, Jane Griffin, Mary Harrington, Ian Hill, Marie McCormick, Renee Schwalberg, Amy Zambrowski, and Beth Zimmerman. "Implementing a Community-Based Initiative: The Early Years of Healthy Start." Washington, DC: Mathematica Policy Research, December 1994.
- Baltay, Michelle, Marie McCormick, and Paul Wise. "Evaluation of the Fetal and Infant Mortality Review (FIMR) Programs in the Healthy Start Programs." Boston, MA: Harvard School of Public Health, November 1997.
- Howell, Embry, Barbara Devaney, Barbara Foot, Mary Harrington, Melissa Schettini, Marie McCormick, Ian Hill, Renee Schwalberg, and Beth Zimmerman. "The Implementation of Healthy Start: Lessons for the Future." Washington, DC: Mathematica Policy Research, November 1997.
- McCormick, Marie, and Lisa Deal. "The National Healthy Start Program: Report from a Survey of Postpartum Women." Washington, DC: Mathematica Policy Research, July 1998.
- Harrington, Mary, Barbara Foot, and Elizabeth Closter. "Using Health Education to Reduce Infant Mortality: The Healthy Start Experience." Washington, DC: Mathematica Policy Research, September 1998.
- Howell, Embry, Beth Zimmerman, and Elizabeth Closter. "Infant Mortality Prevention in American Indian Communities: Northern Plains Healthy Start." Washington, DC: Mathematica Policy Research, January 1999.
- Devaney, Barbara, Barbara Foot, and Dexter Chu. "Case Management in Healthy Start." Princeton, NJ: Mathematica Policy Research, March 1999.
- Richardson, Douglas, Marie McCormick, Embry Howell, Barbara Devaney, and Lorenzo Moreno. "Level of Care Analyses for the National Evaluation of the Healthy Start Program." Washington, DC: Mathematica Policy Research, March 2000.
- Moreno, Lorenzo, Barbara Devaney, Dexter Chu, and Melissa Seeley. "Effect of Healthy Start on Infant Mortality and Birth Outcomes." Princeton, NJ: Mathematica Policy Research, July 2000.

Title: Implementing a Community-Based Initiative: The Early Years of Healthy Start

Authors: Embry Howell, Barbara Devaney, Barbara Foot, Jane Griffin, Mary Harrington, Ian Hill, Marie McCormick, Renee Schwalberg, Amy Zambrowski, and Beth Zimmerman

Date: December 1994

Summary: In January-April 1994 the national evaluation team visited all 15 Healthy Start project areas included in the national evaluation. The project areas included 12 large cities, a cluster of 4 smaller cities, and 2 rural areas, one of which included 19 American Indian tribal areas. The report includes initial findings on program administration, community involvement, public information campaigns, outreach and case management, clinic enhancements, support services, and services integration. The authors concluded that: (1) at the time of the site visits, all programs were in the early stages of program implementation, with not all program elements being fully implemented; (2) all programs planned to use public information/education and outreach/case management as core features of their programs; (3) clinical interventions were not widespread; (4) there was active community involvement in all programs, although it took many forms and in some cases did not include very much grassroots involvement of community residents; and (5) the evaluation faced many challenges in terms of data collection since the management information systems were not well developed in most sites.

Related Reports:

Devaney, Barbara, David Edson, Embry Howell, John Mamer, Marie McCormick, Doug Richardson, Susan Sprachman, and Paul Wise. "National Evaluation of Healthy Start: Year 1 Annual Report." Princeton, NJ: Mathematica Policy Research, November 1994.

Title: Evaluation of the Fetal and Infant Mortality Review (FIMR) Programs in Healthy Start

Authors: Michele Baltay, Marie McCormick, and Paul Wise

Date: November 1997

Summary: The implementation of the Fetal and Infant Mortality Review (FIMR) process was examined as part of the evaluation of the national Healthy Start program. The implementation of the FIMR process over the five-year funding period is described in terms of productivity, barriers and facilitators to implementation, and project expenditures. As of the summer 1996, 14 of the 15 Healthy Start project areas had successfully implemented the FIMR process. Most programs had developed a two-tier review process for examination of case data in which a review by health and social service professionals was followed by a community review. In the period 1993 to 1995, the percentage of fetal and infant deaths reviewed ranged across the project areas, from 4 percent to 79 percent, with a median of 34 percent. The cost per death reviewed ranged from \$600 to \$3,400. The authors conclude that the FIMR process provides an important opportunity to contribute to the knowledge base regarding infant mortality in these communities. The process, however, has important logistical requirements and may require substantial financial resources that might affect implementation of confidential inquiries into infant mortality and other health problems.

Related Reports:

Baltay, Michele, Marie McCormick, and Paul Wise. "Implementation of Fetal and Infant Mortality Review (FIMR): Experience from the National Healthy Start Program." *Maternal and Child Health Journal*, vol. 3, no. 3, 1999, pp. 141-150.

- Title:** The Implementation of Healthy Start: Lessons for the Future
- Authors:** Embry Howell, Barbara Devaney, Barbara Foot, Mary Harrington, Melissa Schettini, Marie McCormick, Ian Hill, Renee Schwalberg, and Beth Zimmerman
- Date:** November 1997
- Summary:** This report provides a final summary of the implementation experience of the 15 initial Healthy Start project areas through the demonstration period that ended in September 1997. Information comes from two rounds of site visits and two rounds of telephone follow-up calls along with focus groups of clients and providers. The evaluators found that the Healthy Start program consisted of the following major components: (1) community involvement through a variety of strategies; (2) outreach and case management to identify women and ensure that they received appropriate services; lay workers provided many of these services; (3) a variety of other nontraditional support services; (4) enhanced clinical services, building on the existing delivery system; and (5) communitywide information campaigns. The conclusions chapter highlights 16 major lessons from implementation in the demonstration phase, among them: (1) the importance of attracting and retaining strong project leadership; (2) the difficulty of defining and achieving consumer involvement, along with some innovative strategies from some projects; and (3) the apparent success of incorporating lay workers into the outreach/case management models, showing promise for improving client satisfaction. Two appendices to this report show detailed time lines for each project and maps for the project service areas.

Related Reports:

- Howell, Embry, Barbara Devaney, Barbara Foot, Jane Griffin, Mary Harrington, Ian Hill, Marie McCormick, Renee Schwalberg, Amy Zambrowski, and Beth Zimmerman. "Implementing a Community-Based Initiative: The Early Years of Healthy Start." Washington, DC: Mathematica Policy Research, December 1994.
- Howell, Embry, Barbara Devaney, Marie McCormick, and Karen Thiel Raykovich. "Back to the Future: Community Involvement in the Healthy Start Program." *Journal of Health Politics, Policy and Law*, vol. 23, no. 2, April 1998, pp. 291-317.

Title: The National Healthy Start Program: Report from a Survey of Postpartum Women

Authors: Marie McCormick and Lisa Deal

Date: July 1998

Summary: This report provides a comprehensive overview of findings from a survey of postpartum women in WIC clinics in the Healthy Start project areas. Both Healthy Start participants and nonparticipants were sampled. Compared to nonparticipants, Healthy Start participants were at higher sociodemographic risk, equivalent in prior obstetric outcomes and health habits, but less likely to use a private doctor's office or HMO for prenatal care. After controlling for these factors, few differences were seen between participants and non-participants with the following important exceptions. Participants were more likely to receive outreach/case management services, be receiving birth control at the time of the interview, and rate their prenatal care as higher in terms of quality and satisfaction. The authors conclude that Healthy Start programs were successful in enrolling women at high sociodemographic risk for adverse pregnancy outcomes. The differences between participants and nonparticipants show little program effect on the immediately concluded pregnancy but potential to influence future reproductive outcomes.

Related Reports:

Devaney, Barbara, David Edson, Embry Howell, John Mamer, Marie McCormick, Doug Richardson, Susan Sprachman, and Paul Wise. "National Evaluation of Healthy Start: Year 1 Annual Report." Princeton, NJ: Mathematica Policy Research, November 1994.

Susan Sprachman, Embry Howell, and John Hall. "Justification for OMB Clearance of the National Evaluation of the Healthy Start Program." Princeton, NJ: Mathematica Policy Research, February 1995.

Devaney, Barbara, David Edson, Barbara Foot, Embry Howell, Marie McCormick, Lorenzo Moreno, Ian Hill, and Luke Henderson. "National Evaluation of Healthy Start: Year 2 Annual Report." Princeton, NJ: Mathematica Policy Research, March 1996.

Deal, Lisa, and Marie McCormick. "Early Postpartum Hospital Discharge Among Low-Income Women in the United States." Boston, MA: Harvard School of Public Health, September 1998.

Title: Using Health Education to Reduce Infant Mortality: The Healthy Start Experience

Authors: Mary Harrington, Barbara Foot, and Elizabeth Closter

Date: September 1998

Summary: Health education programs were designed and delivered in all 15 Healthy Start project areas. Based on data collected during site visits and by the Healthy Start postpartum survey, this report takes a closer look at the many and diverse health education programs. The programs took two basic forms, which the authors classify as “targeted health education” and “community-wide education”. Within the first category are included formal classes as well as one-on-one education offered to clients in home visits. About 85 percent of Healthy Start participants received health education in one or both of these forms, most often through one-on-one contact. The most common types of education included those addressing nutrition, breastfeeding, sexually transmitted disease, parenting, and family planning. These same topics were common ones for the community education campaigns which used a variety of techniques including distributing brochures and newsletters; presentations at health fairs and other public events; and media campaigns, most often by radio.

Title: Infant Mortality Prevention in American Indian Communities: Northern Plains Healthy Start

Authors: Embry Howell, Beth Zimmerman, and Elizabeth Closter

Date: January 1999

Summary: One Healthy Start demonstration was in the Northern Plains, a very large geographic area spanning four states, where 19 Indian tribal communities came together under an umbrella organization, the Aberdeen Area Tribal Chairmen's Health Board. Because the Northern Plains project exhibits features unique to rural Indian communities, such as a higher incidence of post-neonatal mortality, and because it is so large and complex, the evaluation team conducted a special study of that program. As with the broader national evaluation, the Northern Plains evaluation draws on multiple data sources, analyzing data from site visits, focus groups, the project's client data system, a postpartum survey, and vital statistics (birth and death certificates). The project served almost 3,000 clients in fiscal year 1996, the peak year of program operation. The program served a highly disadvantaged group who were similar to clients of the other 14 Healthy Start programs in terms of age and income. The primary services provided by the demonstration were case management and transportation. Authors conclude that the program's emphasis on cultural values was effective, especially for adolescents, leading to the decline in adolescent pregnancy rates that was associated with the Northern Plains demonstration. Adequacy of prenatal care also improved for all women. There was no significant impact of the program on infant mortality.

Title: Case Management in Healthy Start

Authors: Barbara Devaney, Barbara Foot, and Dexter Chu

Date: March 1999

Summary: This report examines the role of case management in Healthy Start, describing (1) how case management was defined and implemented in Healthy Start, and (2) the use and effects of case management services by women residing in Healthy Start project areas. The analysis draws on data from site visits, the project's Minimum Data Sets, and the postpartum survey. Authors conclude that Healthy Start programs have been successful in establishing case management programs in many areas with limited or no prior experience in case management. Site visitors assessed that case management was well established in about half the programs at the time of the visits. Several factors contribute to these variations in the consistency of implementation: (1) those programs with more experience in case management service provision had an easier time implementing Healthy Start case management; (2) programs varied considerably in the use of standard, written protocols; and (3) caseloads in some project areas were very high. The major goal of case management was to improve access to services, increase consumer satisfaction with services, and ensure followup and coordination of services.

-
- Title:** Level of Care Analyses for the National Evaluation of the Healthy Start Program
- Authors:** Douglas Richardson, Marie McCormick, Embry Howell, Barbara Devaney, and Lorenzo Moreno
- Date:** March 2000
- Summary:** One important factor that could have a differential impact on infant mortality rates in demonstration and comparison areas is the availability of neonatal intensive care units (NICU) and, consequently, the number of deliveries occurring in NICU hospitals. To examine this, the authors acquired and analyzed data on neonatal intensive care in project areas and comparison areas. They found that, in general, the pattern in the number of deliveries occurring in NICU hospitals did not change over the demonstration period in either project or comparison areas. One important exception was in New Orleans, where the proportion of deliveries occurring in NICUs went up in the project area but not in the comparison areas.

Title: Effect of Healthy Start on Infant Mortality and Birth Outcomes

Authors: Lorenzo Moreno, Barbara Devaney, Dexter Chu, and Melissa Seeley

Date: July 2000

Summary: This report assesses the effects on infant mortality and birth outcomes of the availability of the federally funded Healthy Start program. It assesses the effects on infant mortality and birth outcomes of the Healthy Start program in all 15 project areas, through 1996 (1997 deaths). Using a matched comparison group cohort analysis of linked birth and infant death records for 1984-1996, the authors estimated regression-adjusted outcomes for each project area, for the following outcomes: adequacy of prenatal care; adequacy of initiation of prenatal care; adequacy of number of prenatal care visits; very-low- and low-birthweight and preterm birth rates; and infant, neonatal, and postneonatal mortality rates. In addition to program variables, control variables included children's sex; plurality; the mother's race, age, education, and marital status; whether there were previous pregnancies; and previous infant deaths.

Healthy Start is associated with improved adequacy of prenatal care utilization in 8 of the 15 project areas; reductions in the preterm birth rate in 4 project areas; reductions in the rate of low birthweight and very low birthweight in 3 project areas, and reductions in infant mortality in 2 project areas. Two project areas S New Orleans and Pittsburgh S have significant improvements in several birth outcomes and reductions in infant mortality attributed to Healthy Start. Three project areas S Baltimore, Birmingham, and Oakland S also had significant improvements in birth outcomes and reductions in infant mortality that were large and close to statistical significance. Philadelphia Healthy Start had significant improvements in all measures of prenatal care utilization and a significant reductions in the preterm birth rate.

Related Reports:

Devaney, Barbara, and Marie McCormick. "Evaluation Design: National Evaluation of Healthy Start." Princeton, NJ: Mathematica Policy Research, December 1993.

Devaney, Barbara, and Lorenzo Moreno. "Comparison Sites for the Healthy Start Project Areas." Princeton, NJ: Mathematica Policy Research, July 14, 1998.

Raykovich, Karen Thiel, Marie McCormick, Embry Howell, and Barbara Devaney. "Evaluating the Healthy Start Program: Design Development to Evaluative Assessment." *Evaluation and the Health Professions*, vol. 19, no. 3, September 1996, pp. 342-362.

Moreno, Lorenzo, Barbara Devaney, Dexter Chu, Catherine Brown, Marie McCormick, and Embry Howell. "Impact of Healthy Start on Infant Mortality and Other Birth Outcomes: Draft Interim Findings." Princeton, NJ: Mathematica Policy Research, October 1997.