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Reducing Infant Mortality

Lessons Learned from Healthy Start

Final Report

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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.