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PolicyLink

Community Involvement in the Federal Healthy Start Program

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A Report from PolicyLink

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Table of Contents

iii	Foreword
v	Executive Summary
ix	Introduction
xi	Purpose and Background of the Study
	Findings
1	A. Overview of Key Study Findings
5	B. What Community Involvement Does for Healthy Start
23	C. Challenges of Community Involvement
33	D. Conditions That Foster Community Involvement
41	Conclusions
47	Policy Recommendations
	Appendices
51	Appendix A: Study Concept
55	Appendix B: Overview of Methods and Analysis
59	Appendix C: Interview Schedule/Questions
63	Appendix D: Focus Group Questions
65	Appendix E: Advisory Board Members
67	Appendix F: Site Summaries
68	Pittsburgh Healthy Start
69	Philadelphia Healthy Start
70	Boston Healthy Start
71	Chicago Healthy Start
72	Kansas City Healthy Start
73	Cleveland Healthy Family/Healthy Start
74	Pee Dee Healthy Start
75	New Orleans Healthy Start (Great Expectations Foundation)
76	New York City Healthy Start
77	References Cited



| Community involvement in Healthy Start has helped mothers to become better parents.

Foreword

PolicyLink is a national policy, research, communications and capacity-building organization advancing a new generation of policies to achieve social and economic equity and build strong organized communities. PolicyLink work is guided by the wisdom and experience of local constituencies.

Established in January 1999, PolicyLink is a new organization. Our connection to infant mortality, however—and, in particular, our involvement in addressing the issue of disproportionate African American infant mortality—spans seventeen years. In 1983, during my tenure as an attorney at Public Advocates, a national public interest law firm, we filed an administrative petition with the United States Department of Health and Human Services. We petitioned the agency to address the high levels of infant mortality in African American communities. That petition resulted in the creation of a national commission that made important recommendations for policy change.

In 1987, during my presidency of the Oakland, California-based Urban Strategies Council, we published information that disaggregated by race and geography various indicators of community well-being—including infant mortality. Subsequently I was asked to serve as chair of Alameda County's Oversight Committee on Infant Mortality. The committee comprised perinatal professionals and com-

munity leaders and was charged with developing local policies to address high levels of infant mortality. This group assisted the County's Health Care Services Agency in applying for and receiving a federal Healthy Start grant for Oakland.

The partners who had come together to explore the problem of high infant mortality became participants in the planning and implementation of the Healthy Start program. These original partners identified others—churches, drug treatment programs, housing services agencies, schools, health clinics, hospitals and political leaders—and began working together to reduce infant mortality.

It was through this process that I met and worked with Mildred Thompson, who became the Director of the Oakland Healthy Start program in the early phases of the program. Through many years of working with her on the Healthy Start consortium, I was impressed with her leadership and vision, as well as her ability to include all the various communities of Oakland. Five years into the program, the County of Alameda Health Care Services Agency moved to apply the Healthy Start principles and practices of community involvement and integrated services to their entire county system of public health care delivery. Mildred was assigned this task as the Director for the newly created Community Health Services Division.

Predictably, as PolicyLink began its work to lift up lessons for policy from local problem solving, we included a focus on the Healthy Start program. I had seen the success in Oakland and how one program had led to deep changes in the County Health Department. We asked Mildred Thompson to lead the PolicyLink Healthy Start project.

The Alameda County story is important both for its Healthy Start program and for the way it proceeded to institutionalize the lessons from the program. For Alameda County Health Care Services Agency, Healthy Start became a lesson in the advantages of community involvement. The leadership of the

agency understood the values of community involvement within the Healthy Start program and recognized that incorporating community involvement mechanisms into other efforts focused on improving children's and families' lives, could provide valuable insights for program development, implementation and improved outcomes. As a result, they sought to embed the lessons of Healthy Start into the operations and programs of the agency and the public health department. Some of the agency transformations included: establishing Community Health Teams (based on the one-stop service oriented Family Life Resource Centers of Healthy Start) to address the integrated health and social needs of families at all stages of life in distressed neighborhoods; requiring department staff, including senior staff, to participate on these teams; starting a high risk infant follow-up program to work with families of low birth-weight babies; and launching the Children and Families First Initiative to expand the services of Healthy Start to the entire county (with funding from state tobacco tax). In addition, the agency applied a community-involved integrated services model to the county's foster care delivery system, and established an Interagency Children's Policy Council (ICPC). The ICPC developed a model to blend categorical funding to deliver integrated health services aimed at improving outcomes for children and families. County officials pursued state legislation to receive the needed approval to pursue this strategy.¹

PolicyLink—by identifying the roles that community residents and organizations have played in addressing health disparities—seeks to assist communities and policymakers in crafting effective strategies that build on community strengths and assets. The following report provides a multitude of lessons for public policymakers to use to develop effective programs that address important public health problems.

Angela Glover Blackwell, President
PolicyLink
June 2000

Executive Summary

PolicyLink Study:
The Role of Community Involvement in the
Federal Healthy Start Program

June 2000

In 1991, when the federal Healthy Start Program was initiated, the United States ranked 22nd in the world in infant mortality. This high rate of infant death was particularly concentrated in African American communities, where babies were dying at more than twice the rate of white babies.

Policymakers who crafted Healthy Start recognized that infant mortality was a result of many factors, related to both health and socio-economic status. To craft appropriate community-based solutions, community involvement was mandated in program planning, implementation and evaluation. Primary responsibility was assigned to local consortia with program participants, residents, community organizations and health care providers as members.

In June of 1999—eight years into the extended demonstration project—PolicyLink initiated a nine-city study of Healthy Start sites to discover the effects of community involvement. Sites studied included Pittsburgh, Philadelphia, Boston, Chicago, Cleveland, New Orleans, Kansas City, New York City, and the rural site of Pee Dee, South Carolina. These sites represented a wide diversity of geographic regions, consortia structures, and variations in grantee organizations from local and state health departments to private non-profit agencies. The majority of sites has been part of the Healthy Start program since its inception.

The study found that sustained community involvement significantly enriched programs.

Community involvement created:

- Community acknowledgement of the infant mortality crisis;
- Effective outreach to families at risk for infant mortality;
- Positive changes in individual behaviors;
- Identification of key community issues that impacted maternal and infant health;
- Innovative programs of health and social service delivery systems to address needs of participants and the community;
- New abilities to address issues of race and racial disparity in health care delivery and outcomes;
- Significant programmatic partnerships that were likely to be sustained beyond Healthy Start's funding cycle; and
- Institutionalized programs, policies and practices that linked health interventions with the achievement of health outcomes.

Findings of the Study

Finding I: Community involvement played a key role in the development and delivery of training and health education, empowering individuals to change behaviors, improve health outcomes and become better parents.

Finding II: Community involvement mobilized the community to achieve health related goals and objectives.

Finding III: Programs built strong and supportive partnerships with community leaders and organizations from health-related and non-health fields that resulted in more comprehensive services and additional resources.

Finding IV: Healthy Start consortia strengthened grassroots civic participation and focused institutional and organizational attention on the needs and concerns identified by the community.

Finding V: Healthy Start consortia helped communities and programs address issues of race, class, and culture.

Finding VI: Community involvement continually enhanced program capacity and community infrastructure.

Finding VII: Healthy Start consortia spurred new programs, policies and practices at all sites.

Finding VIII: To sustain consortia, ongoing institutional investment of training, leadership development, and administrative support resources were required.



| New mother celebrates Cleveland's Healthy Start-inspired "Year of the Child" with her own healthy baby.

Policy Recommendations

This study concludes that the community involvement component of Healthy Start resulted in the development of comprehensive services well-targeted to participants' and communities' needs.

Currently, the Healthy Start program and its community involvement component are under review. Under debate are key questions about whether the program should: continue as is; be authorized as a separate program; or have its funds given to states as part of the Maternal and Child Health Services Title V Block Grant Program. As Congress and the administration face these major choices for the future of Healthy Start, they should ensure that their decision sustains community involvement as a mandated program component. Without this mandate, one of the vital ingredients of the program could easily be lost, and with it, many of Healthy Start's successes.

The clear path to ensuring continued community involvement is to maintain Healthy Start as a separate program maintained by community-level agencies. Healthy Start program funds should not be moved into the Title V block grant unless new specific language and oversight mechanisms are inserted to ensure that community involvement practices will be effectively implemented in communities by state agencies. Congress and the administration should also consider including community involvement mandates in the program requirements of other health service delivery initiatives.

To ensure meaningful sustained community involvement, programs should be required to:

1. Initiate and maintain active, substantive community consortia to participate in the building of integrated health delivery systems.

- Roles for consortia should include:
 - Identification of community concerns;
 - Strategic planning that addresses identified concerns;
 - Identification and recruitment of community institutions to partner in implementation; and
 - Ongoing outreach, monitoring, program development and evaluation.
- Support for consortia should include:
 - High-level administrative personnel to support operation of consortia;
 - Clear guidance and access to technical assistance (including peer mentoring) in the development, governance structure, functioning and sustaining of consortia; and
 - Ongoing training for consortia members and leaders in governance, outreach, program evaluation, leadership and advocacy skills.

2. Focus communities on transforming programs, policies and practices (rather than focusing *only* on individual behavior) by requiring:

- Geographic mapping of factors in the community that negatively impact health;
- Analysis of mapping by diverse community stakeholders;
- Identification of community institutions that can address priority factors; and
- Developing community accountability for specific and realistic annual targets for reduction of negative factors.

3. Require that programs specifically analyze and develop plans to address racial and ethnic disparity in health outcomes. Plans and implementation should address:

- Cultural competency of health care providers;
- Ability to reach target population with services;
- Specific analysis of health indicators by race and ethnic community; and
- Interventions that address specific racial and ethnic disparities.

4. Require linkage with other programs that provide life-long continuity of care and wrap-around services. For example, Healthy Start should either be linked with Early Start or expand its service delivery model to cover the time period from pregnancy to three years of age, when Head Start Services would be available to families.

The many practices of community involvement learned in the Healthy Start program should be continued, expanded and replicated to ensure that the advantages of reaching into a community for program development and implementation are spread throughout the country and the health care services delivery system.

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| Healthy Start consortia meetings typically present health training in an upbeat, interactive atmosphere.

Introduction

In 1991, when Healthy Start was initiated, the United States ranked 22nd in the world in infant mortality.² This high rate of infant deaths was of particular concern in the African American community, where babies were dying at over twice the rate of white babies.³ The decision by the Bush administration to create an initiative to reduce infant mortality, backed by substantial funding, was viewed as a major victory by communities struggling to address this serious public health problem.

With the release of the Federal Register Notice⁴ announcing the creation of Healthy Start, funding became available for sites with the highest infant mortality rates. The goal was to reduce infant mortality in these highly impacted sites by 50% over a five-year period. Through this program, an innovative approach to health service delivery began. The Health Resources and Services Administration (HRSA) indicated that in addition to traditional clinical and access-to-care strategies, this program would pursue an approach focused on consumer and community participation. In fact, one criterion on which cities were chosen was the level of consumer and community involvement demonstrated in their applications for funding. The initial guidance developed by HRSA for programs emphasized this approach: “Consumer participation must be a central consideration in organizing the Healthy Start

project. The participation is expected to be substantive and informed.”⁵ Because infant mortality is a result of many factors, both clinical and socioeconomic in nature,⁶ it was deemed appropriate to involve a wide range of individuals and organizations in seeking effective approaches. Reflecting on the connections between infant mortality, poverty and other problems which play out at the family and community levels, the guidance went on to suggest that “creative community-based interventions should be among the strategies considered.”⁷

The requirement to establish consortia at each Healthy Start site was the major mechanism identified to help catalyze broad community involvement. Guidelines indicated that each consortium would be responsible for oversight of its program, and that its membership should be composed of women of childbearing age, residents of the local communities in which the programs were housed, and providers such as health departments, hospitals, and health centers. Civic groups, professional organizations, churches and schools were also encouraged to participate. This level of community involvement was expected to begin in the planning phase of Healthy

Start and continue through all stages, including evaluation. This mandate calling for extensive, substantive, and consistent community participation was a unique feature of Healthy Start. According to the national evaluators at Mathematica Policy Research, “Community involvement is probably the feature of Healthy Start that most distinguishes it from previous maternal and child health programs.”⁸ Another distinguishing feature was the level of resources allocated for the program. Initially, Healthy Start funded 15 sites on a \$25 million budget. Subsequently, the program budget grew to as much as \$110 million one year, albeit spread over a far larger number of programs.

While instructed not to supplant existing funded programs, Healthy Start sites were encouraged to be creative in their use of resources. The program offerings—of flexible dollars, creativity in program design, a nine-month planning process, a five-year demonstration phase, the freedom to interpret specific community needs into programs to address those needs, and mandated community involvement—all signaled a new era in comprehensive, client-based service delivery.

PolicyLink wanted to investigate the contributions of community involvement both to the Healthy Start project, and to inform other public health and community development policies.

Purpose and Background of the Study

PolicyLink Team

PolicyLink is a national policy, research, capacity-building and communications organization. Its mission is to lift and advance, from the wisdom and experience of local constituencies, a new generation of policies that achieve social and economic equity, expand opportunity and build strong, organized communities. Consistent with its mission, PolicyLink initiated a nine-city study of the Healthy Start initiative to explore the role of community involvement in program development and implementation, as well as site-specific experiences with achieving and sustaining substantive community participation over time. The PolicyLink team included former Oakland Healthy Start Project Director Mildred Thompson, University of California at Berkeley School of Public Health professor and researcher Meredith Minkler, and other PolicyLink staff with expertise in communications, policy development, advocacy, philanthropy, and evaluation.

While a number of useful reports and studies have been conducted documenting both Healthy Start's accomplishments and the challenges it has faced, the critical area of community involvement—from its development and implementation to its roles and outcomes—has lacked sufficient study and attention. PolicyLink wanted to investigate the contributions of community involvement both to the Healthy Start project, and to informing other public health and community development policies.

A national advisory board was convened to provide oversight and assist the project in critical discussion, planning, review and implementation of the project's goals. Membership selection was based on professional areas of expertise, knowledge of the program, and experience with community involvement. Included were: program participants, consortia members, policy advocates, academics, pediatricians, researchers, community building professionals and representatives of the Healthy Start Association and of a major national healthcare

foundation. The inclusion of several Healthy Start consortia members, including participants and community activists was in keeping with the PolicyLink and Healthy Start commitments to, and belief in, the value of community involvement (see Appendix E, page 65 for a list of advisory board members).

Methodological Approach

A multi-site case study design was selected for this research. Each site was visited over a two-day period by the Project Director and one to three other members of the PolicyLink team. Site visits included: interviews with project directors, consortia chairs, other relevant staff and program partners; focus groups with program participants and community consortia members; observation of consortia meetings, service delivery centers, and Healthy Start-related events; and review of site-specific written materials that related to consortia structure, composition and functioning. Interview transcripts were independently reviewed by three research members of the team. A high degree of correspondence was found among reviewers on the themes identified through this process (see Appendices A-D, pages 55-64 for more detail on study methods).

Site Selection

Following discussions with Healthy Start's program and evaluation staff and with our advisory committee, nine sites were selected for inclusion in our study: Pittsburgh, Philadelphia, Boston, Chicago, Cleveland, New Orleans, Pee Dee, Kansas City, and New York City. With one exception (Kansas City), all sites were among the original 15 Healthy Start Programs. Selected sites provided a range of geographic locations and a diversity of consortia structures and varying levels of governance. As indicated above, the primary goal of this study was to explore and determine how the communities carried forward lessons of the Healthy Start experience with community involvement strategies in the nine selected sites.



From left to right: | Mothers welcome having a voice in shaping Healthy Start services. Their participation meets a stipulation of the program's initial federal guidelines. | Pee Dee's Lillie Fox uses a van to transport clients to and from consortium meetings in a remote rural area of South Carolina. | Healthy Start programs support both parents' involvement in a baby's well-being.

A. Overview of Key Study Findings

Community members, program participants and staff are involved in most Healthy Start consortia—shaping programs and overseeing service delivery.



A. Overview of Key Study Findings

Designing well-functioning consortia, similar to the design of new service systems, provided rich opportunities for Healthy Start grantees to collaborate with segments of the community not traditionally included in such efforts. Many sites welcomed this complex, broad-based approach to solving such a major public health challenge and found it stimulating to nurture these new relationships. For others, the mandate to initiate these types of community partnerships was viewed as unfamiliar territory. The consortia that emerged reflected a wide continuum of structures and functioning, from intensive, well-integrated, governance-level involvement, to cursory, limited-attendance, periodic information-sharing meetings. Most consortia had community members, program participants, and Healthy Start staff involved as members. There was variation in the terminology used to describe programs' clients. Some programs referred to their clients as "consumers," whereas others preferred the term "participants." In this report, we use "participants" primarily to describe those who utilize Healthy Start services. Similarly, we learned there was variation of terminology used to describe programs' consortia. Some focus group members appeared confused when we referred to "consortia." They were familiar with "coalition" or referred simply to "meetings."

The terms “consortia” and “coalitions” are often used interchangeably by program participants and directors. However, they represent two quite distinct organizational forms. For the purposes of this study, a community-based consortium is defined as:

“A partnership of organizations and individuals representing consumers, service providers, and local agencies or groups who identify themselves with a particular community, neighborhood, or locale and unite in an effort to collectively apply their resources to the implementation of a common strategy for the achievement of a common goal within the communityThe inclusion of participation of individuals as members is central to the definition of a community-based consortium.”⁹

Coalitions, by contrast, typically are defined as having *only* organizations as members. Also, coalitions usually focus on an advocacy agenda, while consortia focus on planning and oversight.

While many Healthy Start grantees agreed philosophically with the concept of community involvement and the creation of consortia, few had substantive experience with the creation and participation of such groups. A lack of prescribed services, coupled with minimal guidance from HRSA in the initial years on how consortia should be structured and composed, left many programs unsure how to initiate and sustain these community-based entities. And as a handbook describing Healthy Start’s consortia development pointed out, it was “not easy for grantees (who are usually part of a large, bureaucratic government structure) to change the way they conduct business in order to be guided by the community, rather than to have staff devise interventions that will lead to better service delivery.”¹⁰

Our research demonstrated that a range of important resources was garnered for the communities through Healthy Start’s commitment to community involvement processes, and the diverse and creative partnerships they generated. Although a major focus of this study was on consortia, assessment of other community involvement mechanisms was also of interest. One important mechanism involved the use of community outreach workers as liaisons between potential participants and programs. Outreach workers were often well-known residents of the targeted communities and served to increase the credibility of the program. Substantial community involvement also occurred through the awarding of grants and contracts to community-based nonprofit or public agencies for program service delivery. Other ways Healthy Start programs worked to involve the community were through focus groups, town hall meetings, and special events and activities such as health fairs.

This report documents the contributions of community involvement to Healthy Start, and suggests how the lessons learned may be applicable to other programs serving high-risk populations. At the same time, it documents the barriers to well-functioning consortia and other community involvement strategies that were discussed by key informants and observed by the site-visit teams. Finally, the report identifies a number of strategies utilized by program staff and consortia that attempt to deal with and overcome these obstacles, and to elicit increased community involvement in the fight against infant mortality.

Although the experience of each site was unique, a number of cross-site themes were identified. These themes, discussed throughout the report, identified that community involvement played a significant role in:

- Contributing to community empowerment and capacity building;
- Delivering effective public health education and training;
- Linking infant mortality to other issues of concern to the community;
- Building creative partnerships and entrepreneurship;
- Addressing issues of race and class;
- Creating diverse consortia structures and governance roles;
- Resolving provider/participant communication problems within consortia;
- Institutionalizing key program components;
- Addressing barriers to sustained participation; and
- Celebrating success stories at the individual, family, and community levels.

B. What Community Involvement Does for Healthy Start

Community involvement makes an essential contribution to the effective delivery of health services.



| Men's programs at several Healthy Start sites allow fathers to address parenting and family issues in collective ways.

B. What Community Involvement Does for Healthy Start

PolicyLink research revealed that the federal policy guidelines for Healthy Start did translate into programs that take seriously the role of community involvement, and that the community involvement component makes an essential contribution to the effective delivery of health services through Healthy Start. We identified six primary ways in which community involvement contributed to the program and its participants. Community involvement:

1. *Empowered individuals to change behavior to improve health outcomes and become better parents;*
2. *Empowered individuals to take action in the broader community;*
3. *Mobilized the community to work for health related goals and objectives;*
4. *Contributed to community capacity-building and infrastructure;*
5. *Mobilized the community to help bring about changes in programs, policies and practices; and*
6. *Helped institutionalize best practices in the community.*

1. Community involvement empowered individuals to change behavior to improve health outcomes and become better parents

Community involvement played a key role in delivering health education and life-skills training to the community. Across all sites, a strong emphasis was placed on education and training, frequently on multiple levels. On the most immediate level, for example, participants at many sites talked about having developed stronger skills as advocates for their children. A range of topics and skill-building areas were identified and prioritized by consortia members and subsequently covered in workshops and meetings.

CPR, infant first aid, immunizations, family planning and STD prevention, life skills development, parenting classes, GED, English as a second language, and computer classes are a few of the ongoing series of classes provided by most programs. Additional trainings cited as valuable included: understanding how to negotiate complex service systems; understanding and using the “back-to-sleep” method (which sometimes meant challenging traditional family and cultural practices); learning early warning symptoms of pregnancy complications such as pre-term delivery; and learning different ways to manage stress. Cleveland’s consortium invited HMO representatives to explain their various options so that residents could make informed choices in selecting providers. One focus group member felt that her skills were enhanced and knowledge increased as a result of attending these sessions. “Everything I learned through these meetings mattered and was important,” she said.

In Chicago, one young mother praised the consortium workshops for helping her to develop alternative disciplinary practices. She said that she no longer yells at or spansks her children. “I learned about ‘timeout’,” she attested. In the Cleveland

focus group, a mother of three shared how she had stopped using drugs and alcohol and could feel a heightened sense of respect from her children. In New Orleans, a participant shared how her sense of failure at becoming pregnant while in college was shifted to increased self-esteem through her involvement in the consortium and eventual appointment as a member of the board of directors. A program administrator in New York discussed the positive impact observed in participants through their consistent involvement, “Women are starting to question how they deal with their lives. There’s more focus on quality,” she said.

At most sites, caseworkers and outreach workers used their relationships with clients to motivate changes in their clients’ lives and in the lives of their families. Often lacking adequate support systems, consortia members placed a high value on

One young mother praised the consortium workshops for helping her to develop alternative disciplinary practices. She no longer yells at or spansks her children. “I learned about ‘timeout’,” she attested.

such relationships. Usually it was the worker who motivated the client to become interested in joining the consortium, and many times actually provided transportation to the meetings.

Enhanced self-esteem frequently was described as a by-product of health education, as was a tendency among clients to share what they learned with friends and neighbors. A neighbor in New York motivated a pregnant new resident in her building to join her at consortium meetings, which eventually led to her son’s access to computer skills training. A Philadelphia focus group member responsible for bringing a male friend to her “sister-to-sister” program boasted about her active recruitment of others to join Healthy Start. She indicated that prior to Healthy Start, she was very quiet and passive. “Now I have a voice,” she said. “People listen to me.”

Chicago Healthy Start Takes Action

Strong consumer and community involvement has emerged as a hallmark of the Chicago Healthy Start program, which pulls consortium members from the six inner-city neighborhoods it serves. Their consortium includes local business leaders, clergy, community organizations, health providers, the Police Department, schools, and program participants. Quarterly consortium meetings are always well-attended, with participation generally ranging from 60 to 95 people, according to Dr. Wynetta Frazier, Consortium Chair. Dr. Frazier noted that while providers predominated at consortium meetings in the early years, consumers now often constitute the largest single group at meetings, making up 40 to 60 percent of attendees.

What is the magic to maintaining high consumer involvement?

Chicago has found that a number of approaches have worked.

For one thing, the Chicago Healthy Start program takes the consortium and the role of the consumers seriously. A strong emphasis is placed on training consortium members.

The Consumer Mobilization Committee, a sub-committee of the consortium, has been instrumental in getting and keeping consumers involved. Headed by Deborah Thomas, a previous Healthy Start consumer, the Committee's role has been to recruit participants and consortium members as well as to motivate consumers and keep them committed to achieving their goals. Thomas described the recruitment work as "foot soldiering out into the community. You can't be a desk consortium." To keep consumers motivated, Dr. Frazier said it helps to share success stories with them. She makes a point of bringing to these committee meetings examples of successes experienced by current or former consortium members: a successful birth outcome by a high-risk mother; effective and successful advocacy for one's children; or, someone who had gone on to get a job or start a business. "They already come in with their dreams," Dr. Frazier said, "but they need to see someone like themselves who has managed to turn dreams into reality." The Consumer Mobilization Committee played a major role in planning last year's first annual Consumer Conference, which was attended by over 250 program participants.

Although the consortium's role is mainly advisory, Jerry Wynn, Chicago Healthy Start's director said, "We take consumers' input very seriously." For instance, a centerpiece of the Chicago Healthy Start program has been the creation and implementation of five "one-stop shopping" health and social service centers. "This type of service delivery came out of the consortium telling us this was the way to go," Wynn said. In another participant-led initiative, the consortium sought help from the Poverty Law Project in challenging welfare reform's work requirement for parents of special needs children. The waiver that was granted represented a policy change that applied to welfare recipients statewide.

Participant members of Chicago's Consumer Mobilization Committee told stories of numerous ways they were able to use existing but underutilized strengths and talents to obtain needed resources. The Committee provided a voice for many new parents to become more actively involved in Healthy Start activities and to receive trainings and workshops. This group planned and convened a well-attended conference, celebrating their accomplishments and motivating each other to continue active involvement in the consortium. Through these and other means, Healthy Start consortia created opportunities for personal empowerment and built stories of success.

On another level, the skills and competencies developed supported participants' greater civic involvement, return to school, and obtaining jobs with Healthy Start or in the broader community. Chicago linked its consortium members to community colleges for vocational training. They also provided breast-feeding training to mothers, who were later hired as breast-feeding counselors. Leadership training programs in Cleveland and Boston, and Cleveland and New York's hosting of workforce development training exemplified the programs' emphasis on helping clients assume increasing levels of responsibility beyond their immediate family life. Most programs hosted training to assist their clients in negotiating welfare reform, and many adapted the timing of consortium meetings and events to accommodate participants' new work requirements and schedules.

Healthy Start's provision of computer classes, résumé-, job-, and college applications-support, and its practice of hiring clients as outreach workers all exemplified Healthy Start's contributions to strengthening individuals. Regardless of the form taken, however, the provision of Healthy Start-sponsored health education and training was clearly viewed as a key component of community involvement at each of the sites.

Economic self-sufficiency was a key goal for many Healthy Start clients, and multiple Healthy Start efforts contributed directly or indirectly to the achievement of this goal. Some participants gained skills needed to create businesses, allowing them to move from client to provider. Through staff and peer support and referrals obtained through Chicago's consortia meetings, many clients opened their own

New skills and competencies supported participants' greater civic involvement, return to school, and obtaining jobs with Healthy Start or in the broader community.

businesses. For example, the caterer for Chicago Healthy Start special events is a husband and wife who were former participants. One woman began a nail business, another started a tailoring shop, a third opened a flower business, and someone else became a mechanic. One client who loved to bake cookies was able to turn a hobby into a promising business. The networks established through consortia helped in creating business referrals for these entrepreneurs. Both directly and indirectly, these consortia-sponsored activities helped program participants "take charge of their own lives," and in the process, become better parents to their children.

2. Community involvement empowered individuals to take action in the broader community

Healthy Start consortia focused institutional and organizational attention on the needs and concerns identified by the community. Consistently, the research identified how consortia provided a vehicle for the communities' issues and for their agendas to address them. Programs engaged in issues related to specific neighborhoods, such as how to make vendors and merchants more accountable to community needs, and in larger community issues such as domestic violence, substance abuse, and housing. In Cleveland, participants were concerned that a local store was selling tainted meat and that a hospital's use of an incinerator was creating environmental hazards. Residents were assisted in successfully changing these situations.

Several sites provided assistance in securing housing, as gentrification, substandard housing, and other problems related to the lack of adequate affordable housing emerged as community needs. Of particular concern was helping residents stay in their communities so they could continue to have access to their families, friends and support structures, including those provided by neighborhood institutions and programs. In New York, Bronx residents were assisted in gaining access to housing that had been previously abandoned. This attention, which in turn helped people see the links between housing and infant mortality, helped Healthy Start gain credibility among community members.

Healthy Start consortia helped develop leadership skills among participants who could then apply these skills to a broad range of community health issues. The consortia provided concrete ways to both build and focus leadership in the Healthy Start communities. Philadelphia engaged in neighborhood organizing, culling issues identified by residents into action plans for reducing infant mortality. The consortia then developed resident leadership to implement the action plans. Boston trained its con-

sortium members in leadership development and explicitly required engagement of those skills in additional community initiatives—thereby increasing the skill-base of the members while strengthening the ties of Healthy Start to other initiatives. Kansas City's program director reflected on the interactive nature of developing people and improving health systems, "We have a responsibility," she said, "to help people grow and develop—through skill development, and by working with the system to make improvements."

The effects of new community leadership were felt at both the local and statewide levels. The New Orleans consortium took seriously the food access concerns of community leaders, and supported the leadership of community redevelopment partners in locating and developing a supermarket in a target community with no food stores. Chicago leaders successfully stopped a proposal to mandate Medicaid-managed care on a statewide basis. The effort developed from consortium members' concerns that the proposed shift to managed care would restrict their access to current health care providers and needed services. The consortium infrastructure was credited by the members as giving them the ability to analyze the effects on their community of the proposed legislation, and to advocate for what was needed.

One New York consortium member, a mother of a 17-year old and a 12-year old, felt that it was critical for her to demonstrate to her children that community involvement was a family value. "To me it is very important that I let them know that community comes first, that whatever they do in life, [they should] always give back...They see me coming home from meetings and I'm cheerful...It makes me feel good." She also valued the networking opportunities of the consortium. "I've met a lot of wonderful people that...I would not have come in contact with if I didn't take it upon myself to join the organization."

Outcomes of constructive community engagement can be felt far beyond the Healthy Start Program. In both Boston and Philadelphia, project directors acknowledged that community input was increasingly sought by political leaders and others. “Professionals will readily call the community now,” reported Philadelphia’s project director. “The Health Commissioner now listens to our consortium chair!” Boston’s project director confirmed similar experiences. “Our consortium members have been in focus groups across the city for all kinds of issues,” she said. “When they want consumer input, they call Boston Healthy Start.”

Healthy Start consortia initiate and strengthen creative partnerships and alliances that can bring positive change to the community. By strengthening partnerships with the community, programs are assisted in accomplishing several goals: identifying target clients, increasing program credibility, creating unique strategies, and ultimately sharing ownership of the problem and solution. By linking Healthy Start with established, well-respected individuals and community institutions, overall program impact was enhanced.

This research demonstrated many examples of creative partnerships, which formed as a result of Healthy Start’s reaching out to community organizations. Local businesses contributed food and goods for health fairs, sponsored special events, provided technical assistance, assisted in fundraising activities and volunteered services. Target-area churches sponsored “Healthy Baby Sundays,” in which part of a service was focused on increasing awareness about infant mortality. New Orleans reached out to

Bailey’s Casino to underwrite some activities and contribute funds. Cleveland’s “Stork’s Nest” program, which is a partnership between the March of Dimes and the Zeta Phi Beta sorority, provided needed baby clothes and equipment to expectant mothers.

Two programs had strong linkages with Empowerment Zone programs in their cities. Many consortia were successful in forging strong, lasting relationships with schools, housing departments, and neighborhood/tenant associations. Police departments served as recent partners to many Healthy Start sites. Cleveland’s partnership with the jails demonstrated an innovative approach to reaching high-risk pregnant and parenting women in non-traditional settings. The Council for Economic Opportunities was an active partner in Cleveland Healthy Start. New Orleans’s Healthy Start partnered with a mortuary that provided free burials for fami-

Healthy Start consortia helped develop leadership skills among participants who could then apply these skills to a broad range of community health issues.

lies faced with an infant death. Kansas City had strong ties to political leaders and the media. The program drew on these connections to educate politicians and the general public about Healthy Start and its programs, to push for needed revenues for programs and to advocate for policy changes necessary for more effective service delivery. With the help of United Way, the Missouri program director launched a particularly effective media campaign that included public service announcements on radio, television, billboards, and buses.

3. Community involvement mobilized the community to achieve health-related goals and objectives

Typically, prior to Healthy Start, health services were difficult to access for many families in the target communities—they were either physically distant or culturally alienating. Through the programs' creation of collaborations with community members and institutions, new services were established through partnerships in the communities themselves—building an infrastructure where none had existed, and building cultural competency through the attention and guidance of the consortia.

Community involvement increased attention to infant mortality in the entire community. Communities were able to increase awareness both about what infant mortality was and about the connec-

informing the community about infant mortality. Cleveland's Healthy Start community organizers utilized neighborhood events and activities at settlement houses to link infant mortality to larger issues of community concern.

In many communities, non-health-related organizations were actively involved for the first time in the fight against infant mortality through partnerships with Healthy Start. Churches became volunteer partners and subcontractors. They co-sponsored special events and recruited their congregations to work with local grantee agencies. School-based clinics were initiated in some communities. In Boston, a clinic was established in a target-area housing development. One of Boston's consortium leaders said that understanding of infant mortality served as a wakeup call that resulted in increased

involvement by community organizations.

"More and more people are realizing that institutions aren't healthy if the community isn't healthy," she said.

One-stop service sites were established

in target neighborhoods, thereby increasing access to a vast array of services for those most in need. The director of the Northern Manhattan Perinatal Partnership, the organization that administers the Harlem Healthy Start Program, acknowledged the critical role an actively involved community can play in neighborhood-based programs. "We made infant mortality a central public health issue in the community through our involvement of the local media," he said.

Increased understanding of infant mortality resulted in targeted community organizing efforts.

tions between infant deaths and health behaviors. There was a "call to action" by many communities, resulting in mobilization efforts to inform the community and garner support and resources to more effectively address infant mortality. In Philadelphia, consortium leaders said that this increased understanding of infant mortality being highest in certain neighborhoods resulted in a targeted community organizing effort. Many programs depended on consortia members to help frame and launch media campaigns aimed at promoting Healthy Start and

Healthy Start consortia helped the community and the program address issues of race, class, and culture. In 1991, when the program began, African Americans had the highest rates of infant mortality. Today, even with overall rates declining, African Americans remain disproportionately affected.¹¹ By 1999, however, many Healthy Start programs were experiencing major demographic shifts, forcing them to tailor their services differently. Program changes were being made as a result of:

- the emergence of new immigrant populations in targeted communities;
- tensions based on race and politics that surfaced at consortia meetings between participants and providers;
- administrative decisions to make staffing changes more reflective of diverse client populations;
- concerns with insuring adequate representation of agencies and consumers on boards and consortia; and
- efforts to insure that policies and programs are racially, culturally and linguistically appropriate.

Site visit research revealed that community involvement often enhances programs' cultural sensitivity, responsiveness, and comprehensiveness. Few programs had reached the level of diversity and competence they felt was needed, but creative and effective efforts were evident in most sites. In Pittsburgh, it was clear that community activists who had leadership roles in the consortium held the program to a high level of accountability regarding racial and cultural issues, in addition to providing guidance and oversight on overall program operations and standards. Kansas City hosted a conference to address the need for increased awareness and competency related to a growing Hispanic pop-

ulation. Boston's Healthy Start Program printed materials in several languages, including information targeting their growing Asian population. They targeted a large new Dominican population, while Pee Dee, South Carolina reached out to their growing Haitian population. Philadelphia witnessed the arrival of French-speaking Africans in their community. Though initially unprepared to adequately serve these newcomers, each program adapted their strategies to meet the new residents' needs. The cultural demands of shifting demographics required programs to enhance service delivery, adjust program capacity, and strengthen community accountability.

At a number of sites, tensions or communication problems were noted between providers and consumers. In some cases, consumer consortia members felt intimidated by providers. In other cases, providers expressed discomfort at being in meetings dominated by clients. Some felt that extensive consumer involvement was "a waste of time." Race and class differences between providers and consumers were directly mentioned or hinted at in several sites as the basis for these communication problems.

Several sites experienced changes in the composition of their consortia as a result of communication problems or discomfort between providers and consumers. In earlier years at the Philadelphia site, for example, many providers stopped attending meetings because of the strong community activist leadership of the consortium. Consumers got tired, too, as one staff member reported. "Bringing a pregnant woman with two children and sitting her at the table to meet with the CEO...just did not work," she said. Some sites—including Boston and Pee Dee—made a deliberate effort to tip the balance of consortia participation away from provider dominance

and toward grass roots participation. In some cases, provider involvement decreased due to strained relations among these diverse partners. Trainings for consumers on meeting process and protocol, and for providers on cultural competence, were offered at a number of sites to specifically address provider-consumer communication problems.

The director of the rural Pee Dee, South Carolina program reported that she had not been able to obtain an optimal level of racial diversity on her board of directors. “The perception was that [infant mortality] is a Black problem,” she said. Establishing a broader regional health consortium with providers and participants marked an important sign of progress.

Whether within the Healthy Start program itself, or as part of the larger environment in which it operated, race- and class-based tensions continued to emerge as new groups moved into neighborhoods. Some sites discussed tensions between particular racial and ethnic groups (e.g., between Cambodians and Vietnamese in Philadelphia, between Hispanics and African Americans in Chicago, and between whites and African Americans in Pee Dee). Such tensions expressed themselves in subtly nuanced ways. In Central Harlem, for example, when program administrators expressed the need for outreach to the growing Hispanic population, African American staff did not express opposition, but did exhibit a reluctance to move in this direction. Despite these continuing problems, however, the awareness of, and willingness to confront and rectify tensions based on race, class and culture constituted a hallmark of most of the Healthy Start programs studied.

4. Community involvement contributed to community capacity-building and infrastructure

Community empowerment and capacity building were central elements to many of the Healthy Start consortia and were manifested through the building of local infrastructure. The nature of program operation involved the provision of sub-contracts to grass-roots organizations and other local entities that in turn were able to expand their range of service delivery and broaden their networks. One site, Boston, even hired consultants to help 20 of its small community-based subcontractors find alternative funding when Healthy Start’s budget was reduced. New York Healthy Start used its carry-over monies from one budget year to the next to build a state-of-the-art job-training center. Approximately 100 women were trained in computer and related skills between 1997 and 2000, and 80% of those landed full- or part-time jobs earning up to \$35,000 annually. The number of clients who later worked with Healthy Start in either volunteer or paid capacities was one important indicator of Healthy Start’s success at community capacity building. This was particularly impressive in Cleveland, where they had trained and hired 235 community residents as outreach workers. In Pittsburgh, most staff were hired from the community, many of whom subsequently were hired away by other agencies because of the extensive skills they obtained through Healthy Start.

Cleveland’s Healthy Start created health education programs in middle and high schools. Boston’s caveat that all participants in its leadership-training program commit to becoming involved in at least one other community initiative exemplified that program’s contributions to community empowerment. Several Healthy Start programs had become, or were

in the process of becoming, nonprofit 501(c)(3) organizations, an indication of their growing independence and increasing the possibility that their services would continue into the future.

Community involvement strategies continually enhanced program capacity. Many consortia were able to modify programs, expand services or significantly enhance delivery systems as a result of input from participants. This input was not limited to consortia, but included other mechanisms as well, such as focus groups and satisfaction surveys. During the initial planning phase, programs received a great deal of community input. For many programs, input was also solicited during Healthy Start's annual application cycles and during critical budget cuts. The framing of and prioritization of program services constituted critical roles of community involvement at several Healthy Start sites. In Pittsburgh, Healthy Start program staff attested to the frequency and authority of consumers' participation in most program planning and implementation activities. Staff attributed the creation of two residential programs

to their consortia: Healthy Start House (a short-term residential home for pregnant women) and House of Hope (a substance abuse program for pregnant and parenting women). A school-based health clinic in the Bronx was created as a result of direct consumer input. The school focused on pregnant teens, but offered no on-site clinical services prior to Healthy Start. An administrator in Kansas City's program echoed a sentiment expressed by several sites. "[Health care] professionals realize they will not succeed unless they involve the community," she said.

Healthy Start consortia strengthened grassroots civic engagement in each community, creating new mechanisms for problem solving and collective action. Through a dynamic interplay of community organizers hired by the projects, volunteer community activists, outreach workers and case managers, a rich mixture of program participants and the broader community came together in training forums where problems and barriers were identified and active committees formed to address the identified needs. Meetings were regularly scheduled in most communities, and all areas reached out to community members to help identify topics for meetings. New Orleans had a strategic planning process in place, which focused grassroots participation on measurable outcomes for reducing infant deaths, increasing high school completion, lowering violent crime, and achieving other objectives. They granted \$10,000 partner mini-grants when community-based organizations devised plans that would specifically advance one of their strategic goals. In all of the communities, engaging community members in problem solving processes and strategies either did not occur to the same extent or did not occur at all prior to Healthy Start.



| New Orleans' participants access useful resources in their consortium meetings—health education, career support, and leadership training.

5. Community involvement mobilized the community to change policies, programs, and practices

The various mechanisms of community involvement produced unique institutional infrastructure in each community. Consortia knit together the complexity of community institutions in each locale that could address infant mortality in comprehensive ways.

The infrastructures that emerged from community involvement in Healthy Start supported creative program partnerships that enhanced health and social service delivery in the target communities. Consortia members helped identify community institutions and programs whose expertise they could bring to Healthy Start, and partnerships were formed through contracts, grants, and agreements of service delivery.

Cleveland and Chicago programs partnered to bring case management, follow-up, and support services inside the county jails, where incarceration rates of pregnant and parenting women are rising sharply, due almost entirely to drug-related activities. Correctional officials in Cleveland see the partnership as a unique opportunity for “a public health teaching moment,” which can significantly shift a range of behaviors for parenting moms—from stopping substance use, to instilling good nutrition practices, to engaging in extensive study of parenting strategies while confronting their own experiences. New Orleans established one-stop centers for a range of health and prenatal services, but also located housing, childcare, GED support, career counseling, and workforce development training in the same public facilities. Such co-location of ser-

vices in community settings has been shown to reduce fragmentation and enhance utilization among targeted client populations.¹²

Community consortia played important roles in developing well-targeted service delivery. A dynamic process of problem solving existed at most sites. This process included: reports from outreach workers on realities in the field; reports from case managers on the realities of families being served; and identification by consortia members of other challenges in the community. These parties then worked together to identify solutions to the problems. When New York outreach workers noted that 80% of the women in their program had been involved in domestic violence, the consortium made the development of an effective domestic violence prevention and response component of their program a high priority. They provided intensive training to 19 domestic violence peer educators and engaged clients in developing a training video on the problem.

When consortium members in Pee Dee, South Carolina analyzed the barriers to families receiving regular medical attention, they devised a supportive system of transportation to help women keep on a preventive track of medical care. When Cleveland outreach workers noted the displacement of pregnant women from housing due to gentrification in the central city, they came to the consortium to devise focused new housing partnerships that could find families emergency and long-term affordable housing. Pittsburgh created an extensive male outreach and support program after its consortium prioritized the constructive involvement of the fathers in their children’s lives.

Healthy Start consortia played key roles in identifying community needs and working to attract complementary funding streams that could address those needs.

Community Participation: A View From Pee Dee, S.C.

Two nights a month, Lillie Fox gets in a van emblazoned with the Healthy Start logo and makes the rounds, picking up clients for a meeting to discuss an important community issue. To get to the meeting, Fox must drive down desolate country roads and through endless miles of cotton fields. Fox lives in the Pee Dee region of South Carolina, a sprawling agricultural area with few industries, a paucity of hospitals and an extremely high number of infant deaths.

Fox is in charge of maintaining community relations in the Pee Dee Healthy Start Program, one of 94 sites receiving federal funding for a demonstration project begun in 1991. She represents one of the program's unique approaches to lowering the nation's infant mortality rate—community involvement.

The area's sprawling rural terrain makes the lack of public transportation and telephones a major challenge. Fox and her van provide a crucial support. Fox goes out of her way to make sure folks get to consortium meetings. She believes it is important to hear the voices of consumers. Without their involvement, she said, "you wouldn't know if what you were doing was working. They are the backbone."

Consortium meetings represent yet another of the program's unique features. Held at regular intervals throughout the year, these meetings of clients, providers and community leaders help shape health care strategies best suited to meet the needs of their area.

Healthy Start consortia built constructive links between community organizations and health departments, creating more effective public health communication and targeting strategies. Healthy Start played innovative leadership roles in many communities at the intersection of health and social concerns. In New York City, Healthy Start formed a strategic alliance with the Children's Defense Fund and the local health department to undertake aggressive outreach regarding immunizations. The program continued to host monthly meetings of a

citywide immunization network. New York's consortium further took the lead in forming a citywide consortium of over 20 male involvement programs that it convened regularly.

Healthy Start consortia played key roles in identifying community needs and working to attract complementary funding streams that could address those needs. The New York program consistently sought alternative funding to continue its male involvement projects after funding cuts by HRSA to expand the number of Healthy Start cities. Consortia

members insisted that men were too important to the lives of the children to have this component dropped, and turned their attention to finding other funding sources. New Orleans raised Ryan White AIDS funds to support supplemental program services for their clients. Where consortia have considerable overlap with economic development leaders in their community, funding streams have developed with family and infant-health in mind.

Healthy Start Consortia developed new nonprofit institutions in several communities, creating community-focused institutions where few had existed. The development of separate Healthy Start nonprofit institutions in several communities came about for different reasons and took different organizational forms. In Pee Dee, the program felt that its fiscal sponsor could not deliver the administrative and program support the program required, and split off to develop its own capacity. This decision resulted in a strong African American-led nonprofit, but the program sacrificed some support from the mainstream white community in the transition. In Pittsburgh, the 501(c)(3)-authorized organization formed by the Health Department is integral to the agency, and uses its autonomy to manage alternative funding streams and to hire outreach workers directly from the community. Despite their diversity, the formation of each of these Healthy Start nonprofits was an important symbol of community commitment to institutionalizing the local Healthy Start program.



| Outreach workers who are known by the community bring credibility to the program and attract participants.

6. Community involvement helped institutionalize best practices in the community.

Institutionalization of programs took place when best practices were integrated into ongoing work of health departments or into other partnerships. While governing consortia played a role in prioritizing issues for the community and the program to address and in developing responsive strategies and programs, some shifts in program were also attributed to administrative priorities. Where the implementation of these programs strengthened the communities, consortia and staff sought vehicles for institutionalizing the practices. Examples of these best practices included:

Pittsburgh

Pittsburgh created a Male Initiative Program, which provided an effective model for engaging fathers through outreach, case management, and support groups addressing topics such as anger management, domestic violence, substance abuse, relationships and parenting. Career assistance was provided and a monthly series of workshops on men's health was offered. The program distributed resource guides and other informational materials to participants and community members. Other examples of Pittsburgh's institutionalization of programs included:

- Creation, in partnership with Braddock Hospital and Family Health Council, of two residential programs for clients: House of Hope, focusing on pregnant and parenting women with substance abuse histories, and Healthy Start House, for prenatal, or postpartum women needing short-term residential care.
- Integration of Women, Infants and Children (WIC) clinics into prenatal hospital centers;
- Facilitation of increased provider responsibility in maintaining consumer participation; and
- Implementation of literacy programs to promote parents reading to children.

Philadelphia

Philadelphia's program, in partnership with the City of Philadelphia, implemented an extensive neighborhood-lending closet, with cribs, car seats, strollers, clothes, and other goods for expectant and new parents who cannot afford to purchase needed items. More than 300 parents were served annually, allowing families to keep items for up to a year. Support groups were also offered to those receiving this service. Additional examples in Philadelphia included:

- Implementation of Town Hall Meetings in target areas to elicit community input on how the program is operating and ideas for the future;
- Implementation of peer empowerment debate team for teens;
- Creation of Health Corners, a nurse-based clinical facility serving pregnant women; and
- Creation of an Asian Advisory Committee to ensure that this community's concerns were addressed by the program. This body was later integrated into the health department as well.

Boston

Boston Healthy Start implemented Community Outreach Worker Training through five tenant associations in different areas of the city. Forty women trained in the program were hired as outreach workers by community organizations. The Boston Housing Authority continued support for these trainings when Healthy Start funds were cut. Other activities institutionalized in Boston included:

- Promotion of consumer participation in many city organizations;
- Creation of GED and ESL classes, with subsequent location of new funding streams for these programs; and
- Establishment of a health center within a public housing facility.

Chicago

Chicago's consortium has played an active role in shaping the implementation of welfare reform laws in Illinois. Through the active role played by the Consumer Mobilization Committee and the larger consortium, parents won a waiver policy to allow a deferment of work requirements for TANF parents of special-needs children. Other accomplishments included:

- Leadership, by the Consortium and Healthy Start, of a successful effort to oppose mandatory managed care;
- Creation with Cook County Jail of a program for pregnant incarcerated women; and
- Advocacy for the development of one-stop-service sites by program participants.

Kansas City

Kansas City expanded its KC WAIT program through Healthy Start and its consortium. This teen pregnancy prevention program, funded by the CDC for five years, required a fully functioning consortium during implementation. Healthy Start helped KC WAIT involve a range of community partners—including active clergy—to participate in the program. Other efforts included:

- Support for bilingual staff and translation of health education materials to meet needs of a growing Hispanic population in the target area; and
- Hosting of a conference that addressed cultural issues for Hispanic participants.

Cleveland

Cleveland implemented a mobile health van that served at-risk residents in targeted locations, such as social services facilities and other public service sites. Nurses on the van conducted HIV testing, other STD screening, blood pressure monitoring and referral of clients for appropriate follow-up. This served as a first line of intervention for hard-to-reach populations. Additional successes noted in Cleveland were:

- Replication of Healthy Start's outreach model through a grant from Cleveland's Infant Mortality Reduction Initiative to serve four non-Healthy Start areas;
- Creation of Stork's Nest program (partnership with March of Dimes and Zeta Sorority) providing baby clothes etc. to expectant mothers in need; and
- Initiation of an innovative program in correctional facilities to serve pregnant and parenting women, providing case management, parenting classes and follow-up after discharge.

Pee Dee

Pee Dee Healthy Start in South Carolina, representing six rural counties, obtained the continuation of funding for its ROADS Teams (Rural Outreach Advocacy and Direct Service Teams), through the health department and private nonprofit funding, following the elimination of Healthy Start funds. (Home-based services and adequate transportation were essential for residents of this remote area.) Other examples of institutional commitments included:

- The continuation of Fetal Infant Mortality Review (FIMR) to health department;
- Successfully working in a leadership role for the consolidation of the Medicaid application process;
- Initiation of a Male Outreach Program; and
- Creation of a new Healthy Start nonprofit.

New Orleans

New Orleans developed a comprehensive strategic plan to better address the acute needs of the specific neighborhoods in the community. Site-specific programs and goals were developed to reduce infant mortality, school dropout rates, and violent crime. The program in turn trained consortia members in budget development and evaluation plans. Other activities cited by Great Expectations/Healthy Start were:

- Development of multi-service sites to better integrate services;
- Successful integration of a network of diverse providers;
- Forging of creative collaborations with non-traditional partners (including a casino and a funeral parlor), and strong mayoral participation; and
- Creation of a new Healthy Start nonprofit.

New York

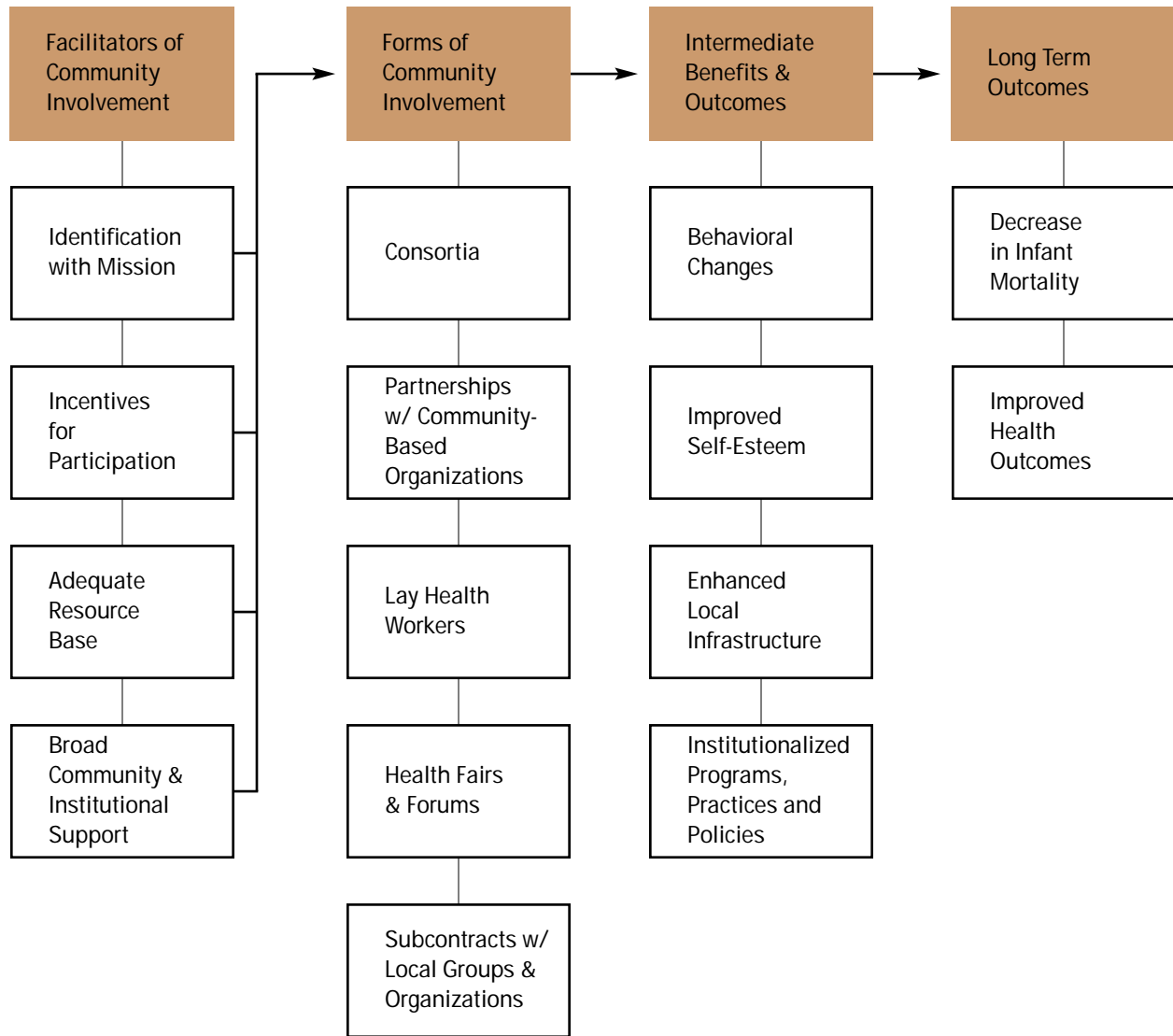
New York's Healthy Start Program assisted in the creation of a citywide consortium of over 20 male involvement programs. This consortium represented a wide range of agencies providing services and support to men in New York City. New York successes included:

- Development of a Bronx high school-based prenatal care clinic;
- Creation of a state-of-the-art computer training center in Central Harlem, using Healthy Start carry-over monies; and
- Development of a nurse midwifery program at a local hospital which provided continuity of care for patients receiving prenatal care at local community centers who delivered at the facility.

See Appendix F, page 67, for summaries of each site's programs.

Figure 1

Community Involvement: Facilitators, Forms, and Benefits



Community involvement contributed to Healthy Start in a multitude of ways, ranging from empowering individuals to become better parents to mobilizing communities to help change programs, policies, and practices. As suggested in Figure 1, these benefits of community involvement may also be seen as intermediate outcomes, which in turn lay important groundwork for the achievement of Healthy Start’s long-term goals of reducing infant mortality and improving health outcomes.

In Male Outreach Program Fathers Matter

One of the strengths of the Pittsburgh Healthy Start program has been its emphasis on outreach among the male population, a sector of the community that is often overlooked but plays an important role in maintaining healthy infants. The Pittsburgh male initiative program targets young fathers aged 15 to 25 in six regional service areas through schools and in public housing communities. As described in the program brochure, the goal is to “inform fathers and other male support persons how extremely influential they are to the outcome of a pregnancy, and to the ongoing health and well-being of their babies.”

Program services are geared toward improving the father’s knowledge of pregnancy, childbirth, parenting and enhancing his support to the child and family.

Jay Darr, manager of the male initiative program, said that, to date, the program has served nearly 300 men through case management and has reached almost 900 youth in the schools.

“We have a philosophical perspective,” said Carmen Anderson, executive director of Pittsburgh’s Healthy Start. “Children with two parents do better than those with only one. It doesn’t have to be a traditional family relationship, but that certainly helps. Economic support is also better with two parents.”

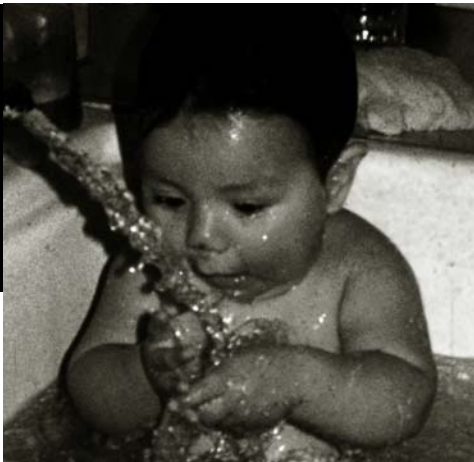
One of the program’s policy briefs makes it clear that the Pittsburgh Healthy Start program endorses the view that “the strategies to bring about a reduction in overall infant mortality must be as complex as the underlying issues that contribute to it in the first place.” With its male initiative program, Pittsburgh is on the right track.



| Pee Dee’s Male Outreach Worker June Wright (left) and participant Jermaine Rodgers collaborate to create a dynamic program for fathers in South Carolina.

C. Challenges of Community Involvement

Consistent engagement of community institutions helps create joint community and staff ownership of the Healthy Start program and its goals.



From left to right: | A healthy baby is the goal of the nation's Healthy Start program. | Philadelphia's Healthy Start participants, shown here with staff, provide input on a range of community and health issues that affect infant mortality.

C. Challenges of Community Involvement

The value of involving community members and program participants as more than just recipients of services in programs such as Healthy Start has been documented in several recent studies.¹³ At the same time, there are very real challenges in initiating and sustaining meaningful, high-level participation.¹⁴ Measured against the criteria set forth in Arnstein's classic "ladder of participation,"¹⁵ which characterized participation as running from manipulative and tokenistic forms of involvement through "citizen control," many community health programs that claim to emphasize community involvement in fact achieve participation at relatively low levels. Program participants thus may be informed or consulted, but are far less likely to be part of a real partnership for program planning and implementation or to have the managerial powers that correspond to the higher rungs on the ladder.¹⁶

Although the Healthy Start programs showed participation of providers and community members at many levels, most sites appeared to aspire to real, rather than tokenistic forms of involvement, and were engaged in efforts to overcome the barriers to such higher-level participation. At the same time, there was an uneven array of consortium development and level of functioning across sites.

Few programs had governance level consortia. In part, this finding reflected the fact that some programs used consortia, coalitions or groups in place prior to Healthy Start to help pave the way for real partnership development, while others were required to start from scratch. Other factors also contributed to the difficulties associated with creating and maintaining meaningful mechanisms for community involvement. As suggested below, these included issues of power and control, competing community issues (e.g., housing, substance abuse and unemployment), resource limitations affecting the ability to adequately staff the consortia and engage in intensive outreach, and a host of leadership and group process issues. Although we address these challenges separately in terms of their relevance to *initiating* and *sustaining* consortia and other community involvement efforts, clear overlap occurred, and many of these challenges emerged in relation to both the initiation and maintenance of community involvement.

Challenges in Initiating Consortia and other Community Involvement Efforts

Among the most important challenges to initiating consortia and related community involvement processes were a host of issues associated with getting community members and prospective participants to believe in the purpose of the program and the process of community involvement. In many places, the initiation of the Healthy Start program confronted a community perception that infant mortality was a not problem that should be viewed as a community priority. Across sites, focus group members spoke of the need for Healthy Start to address issues of greater immediate concern to residents, including substance abuse, depression and other mental health problems, domestic violence and the lack of job skills development, particularly for youth. Focus group members in three locations similarly suggested that to increase their relevance to the community, Healthy Start services should extend beyond the child's first birthday. In the words of one young mother, "They [Healthy Start clients] should be able to go [for services] whether you've had a baby or not." At another site, a similar sentiment was voiced. "Acknowledge me as a woman, not just as a parent," said one woman. "I have needs after this baby is born." The need for more male services and for helping to overcome male isolation also was stressed, particularly by the lone males who participated in focus groups at five of the sites. As some of these sites formerly had included male-focused programs, their recent elimination due to budget cuts was of real concern.



| New Orleans' Healthy Start (Great Expectations Foundation) brings women from diverse communities into mutual learning about successful parenting.

Even among community members who recognized infant mortality as a serious problem in and of itself, there was often a lack of understanding of the relationship of mortality to the health and lifestyle of the mother. Such gaps in knowledge and beliefs presented still another obstacle to creating joint ownership of the program by the community and program staff. In the absence of an understanding of the problems by the communities themselves, meaningful community involvement could neither be initiated nor sustained.

transportation, and typically offered refreshments at meetings. Kansas City recognized the unfamiliarity with the “culture” of meetings and proposed conducting trainings and discussion sessions for program participants prior to consortium meetings. This training built participants’ confidence and created opportunities for relationships to develop among attendees, translating into a more supportive atmosphere in consortium meetings.

In some places, educating key community leaders became a pathway to changing the broader com-

munity’s knowledge about and perception of infant mortality. In Pittsburgh, the leadership of several community activists had been sustained over many years. They proved key in galvanizing meaningful community involve-

ment for Healthy Start. For other programs, reaching out to clergy and other community leaders was the most critical step in convincing the community that infant mortality was a community problem that they should work to solve.

A key step for all programs that had initiated and sustained meaningful community involvement was having program staff, including directors, show their willingness to listen to community concerns and suggestions and to act on them. Large bureaucracies and grantee organizations had to develop increased sensitivity to community members and show support for consortia development. When this support was displayed consistently over time, trust generally developed among staff, community members and program participants, and the desired joint community-program staff ownership of the program emerged.

To overcome the most immediate barriers to participation, programs offered reimbursement for childcare and transportation.

Initial challenges to consortia development were further complicated by community members’ and particularly prospective participants’ lack of experience going to meetings and understanding how they worked and how to make useful contributions. Community members sometimes felt intimidated by providers, and were ill-equipped for their roles as group members. Barriers to participation included balancing the competing needs and challenges many individuals and family members faced in their daily lives. Some of these challenges, such as lack of childcare, posed real obstacles for new mothers wishing to be actively involved in regular meetings and other program activities.

Programs used a variety of strategies to combat these initial challenges. To overcome the most immediate barriers to participation, for example, programs offered reimbursement for childcare and

Table 1	Challenges to Sustaining Consortia and Community Involvement Efforts
	<p>Challenges from systems or environment</p> <ul style="list-style-type: none"> • Bureaucratic nature of the larger systems (such as Health Departments within which Healthy Start programs are housed) can discourage community initiative • Competing community priorities overshadow program priorities (e.g. housing or jobs) • Race- and class-related tensions (in the larger society, in health services agencies and within consortia) can dissipate goodwill of community leaders • Demographic shifts require new cultural competencies, making outreach difficult for existing staff and community leaders
	<p>Leadership and group process challenges</p> <ul style="list-style-type: none"> • Lack of strong leadership and/or facilitation skills on the part of consortia chairs • Lack of training of consumers for their roles as consumer representatives • Insufficient training for—or familiarity with—how to establish consortia • Consumer consortia members feel intimidated by providers or vice versa • Meeting culture unfamiliar to many consumers • Imbalance in proportion of providers, consumers and community members • Inconsistent participation by consortia members • Interpersonal tensions and communication difficulties based on race or class • Power struggles and control issues among groups, and between committees and executive bodies • Hidden agendas and dominance of meetings by groups or individuals
	<p>Resource Variables</p> <ul style="list-style-type: none"> • Insufficient time to achieve ambitious program goals and objectives, (which in turn means inadequate consortia-development time) • Labor intensive nature of consortia & other community involvement activities • Limited consumer time for volunteer work/competing demands • Inadequate resources to provide necessary incentives to participation • Budget reductions resulting in cutbacks in consortia staff & outreach workers • Imbalances based on money, with providers funded by Healthy Start perceived by some to have disproportionate power • Loss of some providers when their funding was eliminated

Challenges in Sustaining Consortia and Related Community Involvement Processes

Many of the factors that had an impact on the initiation of consortia (and other community involvement efforts) also influenced programs' ability to maintain involvement over time. This included the need to train participants for their roles in consortia and other program capacities, and the need to carefully craft appropriate roles for participants, community members and providers. In addition, a number of specific challenges were associated with sustaining consortia over time. (See Table 1, page 27.)

To function well, consortia needed effective structures, clear roles and strong leaders. Without these, power struggles and control issues emerged between committees and executive bodies, and between consortia and grantee agencies. Cleveland's administrators reported how difficult it was to maintain organizational diversity in their consortium meetings, "Hospital representatives have dropped away," their director reported. "Even Ob-Gyn's don't come anymore." Obtaining a balance of providers, participants and community members to maximize participation and promote shared ownership of the agenda required constant vigilance. Some programs developed by-laws, policies and procedures manuals and initiated "Roberts Rules of Order" in an attempt to train consortia members and formalize their consortia processes.

Even with such inputs, however, project staff often found themselves juggling the balance of power between creating well-prepared community members and creating comfortable consortium roles for providers. New Orleans' project director thus spoke of the delicate balancing act that must be maintained in sharing power with the community. "[The challenge is] how to get their input," she said, "but not surrender control."

Focus group members in several sites advocated greater community power and control. In two sites, for example, community residents felt strongly that the consortia should be a separate entity and

specifically a 501(c)(3) nonprofit, distinct from Healthy Start. One community activist who had been involved with Healthy Start since its beginning, commented that: "There are lots of power and control issues in this consortia. We need more control over the budget and in making major decisions." At another site, a community member similarly suggested that "We should be separate. We can accomplish more."

Issues of power and control sometimes were further complicated by past history, since Healthy Start communities, with their myriad challenges, often served as easy targets for research studies and pilot projects, which could result in skepticism and distrust. Building trust and obtaining needed buy-in takes longer under these conditions. Two focus group participants commented on a feeling of being "ripped off" by people coming into their neighborhoods, taking information from them, creating programs and not crediting the community for having participated in the program design. A consortium leader shared a similar concern, "People come into these communities...start programs, and act like they don't need that local person next door to be involved." Clarity of purpose, expectations and roles was critical to overcoming community distrust, facilitating increased community ownership and retaining a strong commitment to the program's mission and goals.

To confront the challenges that almost inevitably emerged in sustaining consortia, skilled leadership was needed. Tensions based on race, political beliefs, class, and cultural differences sometimes resulted in a lack of trust and a decline in participation by key stakeholders. In these cases, without skilled leadership to negotiate tensions and sort through conflicting priorities, the group could falter or stagnate. Staff in Philadelphia shared examples of providers leaving consortium meetings feeling frustrated with the process, "Some of the clinical providers got really tired of the community," one staff member reported. "They got tired of consumers' fist-in-your-face approach."

Consortia: “Leadership Matters”

“Community involvement is the key to the success of the Healthy Family/Healthy Start program,” Don Slocum says launching into a discussion of his work with the Cleveland version of the federally funded initiative. Housed in the city’s Department of Public Health, the Cleveland program enjoys the support of Mayor Michael White who heads its Executive Council. White declared 2000 the “Year of the Child,” and paid tribute to Healthy Start at its inaugural celebration.

Slocum is chair of the Cleveland HF/HS program consortium. This consortium is the community component of a program that includes eight centers serving 1,000 clients in 15 different target neighborhoods with high rates of infant deaths. The key to the success of this health care initiative, Slocum insists, is the ability “to give the community a voice in shaping the policies and programs that serve their needs and affect their lives.” The mechanisms which make that possible—neighborhood consortia and the consortia leadership committee—consist of program participants, community leaders, volunteers, church leaders, business people and program staff that meets regularly to discuss program planning and implementation.

Slocum points out that this community is also his home. Today, it is very different from the tight-knit community he knew four decades ago as a youth before the Glenville riots rocked the city in 1968. Urban blight has since set in. When it came time to develop the Healthy Start consortium for each local area, Slocum used the organizing skills he had picked up doing civil and welfare rights work. Consumers and residents were invited to the table and encouraged to play key roles in the process.

“The key to developing community leadership is honoring the community’s voice,” Slocum says. “That doesn’t mean just giving people honorary status at the table—but real decision-making power. People want to know ‘What about drugs?’ ‘What about housing?’ ‘What about crime?’” Through listening to the community perspectives, the Cleveland Healthy Family/Healthy Start program has created programs which address their concerns.

Slocum is not the only consortia head who understands the value of community involvement. On occasion, consortia have been so effective that state and local governments have borrowed “the Healthy Start model” in an effort to improve their own agencies. The warden of the Cuyahoga jail approached the Cleveland Healthy Families/Healthy Start program with a request that they set up a program in the city jail. The result was a program that introduced young mothers to key aspects of Healthy Start—health care, life skills and health education—with a system to continue their participation once they reenter their community.

Consortia leaders, like Cleveland’s Don Slocum, are responsible for honoring community felt needs and linking them to infant mortality. They also help to create the climate where consortia can become the source of ideas for new programs and effective implementation.

Consistent participation over long periods of time was a particular challenge for community members serving as volunteers. Constant reminders and encouragement to attend consortium meetings and activities were required. Consortia leaders reported that nurturing consortia relationships required as much time, skill, and dedication as those required of case managers to successfully work with their clients. New Orleans' Project Director reported that "persistent community engagement" was the key to sustaining the interest of community members over long periods of time. In many cases, this required dedicated staff attention. Although many programs initially had this level of staff effort dedicated to address consortia follow-up and related needs, all of these programs were forced to reduce personnel during budget reductions following the expansion of Healthy Start sites.

Funding cutbacks had negatively impacted many programs' ability to maintain optimum levels of community involvement. The elimination of key staff, critical to support of community involvement, created special challenges to sustaining consortia. In New York, for example, budget cuts resulted in the consortium continuing to operate, but without its previous "zest." Budget reductions also resulted in a more limited role for consortia at some sites. A few programs reduced the number of meetings from monthly to quarterly. Other programs reduced or combined committees. Funding also played a role in some programs' ability to sustain provider participation in consortia. Some providers funded by Healthy Start were perceived to have disproportionate power and influence while others, whose budgets were cut, discontinued their consortia involvement.

Beyond the consortia, budget cuts also resulted in reductions in outreach and related activities that in turn sometimes negatively impacted community involvement. In Pee Dee, for example, where budget cuts had reduced the number of outreach workers from six to three, the program was forced to focus

on certain geographic areas within its broad 100-mile radius. Ironically, in the face of such cutbacks, focus group members at six sites stressed the importance of *more* aggressive outreach, including additional attention to advertising and media campaigns. One mother of four said, "I know lots of mothers on the street that don't know about this place [Healthy Start] and don't know they can get prenatal care here." A participant at another site remarked that she knew about Healthy Start only because her aunt happened to work at the program. Another mother expressed her view that more outreach was needed. "There should be posters and flyers all around the neighborhood, in the schools, in the clinics," she said. "People need to know that we're here." With recruitment of new Healthy Start participants critical not only to meeting program targets, but also to building community infrastructure, cutbacks that resulted in decreased community outreach were of concern on multiple levels.

In the face of the myriad challenges to initiating and maintaining strong consortia and other community involvement activities, many programs have demonstrated unique, creative approaches. Some programs, for example, have been very creative in adapting staff roles to meet the changing needs of their consortia as they developed. Boston's Project Director now shares responsibility for convening consortium meetings with two other staff members, on a rotating basis. Kansas City had a staff member who reported spending lots of her time on meeting planning. On another front, some programs have increased their use of clients as informal outreach workers. A staff member in New York, for example, commented that fully 20-25% of all new Healthy Start clients at her site were recruited by friends or relatives who were current or former program participants. It was hoped that some of these new individuals would go on to join the consortia and participate in other program activities beyond the receipt of services.

Many of the diverse strategies employed to develop and sustain consortia, and other community involvement processes were discovered through trial and error and a commitment to making community involvement happen. Consistent with its decision to encourage local flexibility in program planning and implementation, HRSA initially provided little training to help program staff understand and tackle the challenges they were likely to confront. With the expansion of the program from the initial 15 sites, new training and mentoring programs were added to help the staff of the new programs understand the challenges associated with community involvement and develop an array of strategies to employ. Especially in the peer-mentoring phase of the program, there was great interest among staff in learning how other programs structured and operated their consortia. As a result, the additional training facilitated the adoption of new practices and policies.

Pittsburgh and Boston conducted technical assistance workshops and trainings in consortia development, providing needed guidance to new and established programs. Cleveland actually conducted a formal evaluation of its consortia from initiation through the demonstration phase. This study was conducted by the site's local evaluator, based at Case Western Reserve University.

In sum, initiating and sustaining consortia and other community involvement processes and efforts was found to require creativity, persistence, consistent resources, and the right mixture of personalities and strategies. Clarity of purpose, expectations and roles was particularly critical to sustaining successful consortia. Overcoming barriers of distrust, addressing competing community needs, and creating a sense of ownership were vital both to consortia development and to initiating and sustaining community outreach activities. Although many programs have responded creatively to budget reductions, and have managed to sustain impressive consortia and related community involvement efforts, the cutbacks have resulted in reduced outreach and consortia functioning at many of the sites.



| Cleveland Mayor Michael R. White celebrates community members' contribution to Healthy Start's successes.



From left to right: | Cleveland mother is proud that what she's doing for her child is working. | Boston program salutes fathers at a ceremony that affirms their role in fighting infant mortality. | Inset: Certificate given to Healthy Start fathers at April 2000 award ceremony.

D. Conditions That Foster Community Involvement

Community involvement requires ongoing training of members in governance, outreach and leadership skills.



D. Conditions That Foster Community Involvement

As suggested throughout this report, the use of consortia and other community involvement strategies for problem solving and service delivery involves “a dynamic process which requires significant attention in order to achieve success.”¹⁷ In the context of Healthy Start programs, many of the conditions fostering community involvement fit within a framework comprised of four major categories: broad institutional support, adequate resource base, incentives for participation, and identification with the program and its mission. Although frequently overlapping, these categories are discussed separately to highlight the strategic mix of conditions that foster community involvement.

Broad institutional support

Support from local organizations and institutions was one of the essential conditions for initiating and sustaining well-functioning consortia and other community involvement mechanisms. Perhaps most critical was the existence of a strong and positive relationship between the grantee agency and the community. In Boston, for example, an early commitment to a 50-50 partnership was reflected in the placement of the consortium on the same level as the grantee agency, the Department of Health and Hospitals, on the organizational chart. Meeting

Sustaining Consumer Involvement

“One of Healthy Start’s great strengths is the willingness to have people who receive services be involved in input,” said Madie Robinson, Pee Dee Healthy Start director.

“It isn’t easy to maintain the involvement of consumers who aren’t always comfortable in meetings or relating one-on-one with professionals,” Robinson added, “but it’s worth it.” Robinson provides training sessions to boost participants’ self-confidence, while also working to meet their childcare and transportation needs.

According to consumers, these efforts are paying off. Many say the program has helped change their lives, made them better parents and provided them with positive reinforcement. “Meetings lift me up. There is always someone to motivate you, to help you keep your goals in mind,” said Vicky Jacobs, a 22-year-old who has found better living accommodations through Healthy Start. She is an emerging leader, serving as the chair of her county’s consumer group.

Also, thanks to the program’s commitment to community involvement, residents in Pee Dee view infant mortality not as an isolated issue, but as one connected to a host of other issues plaguing their community, including unemployment, poverty, substance abuse, sub-standard housing and domestic violence.

Community involvement has groomed a new crop of community leaders like Fox who has become an advocate and national spokesperson for Healthy Start. Community involvement has also broken down barriers, created new relationships and increased community willingness to work together.

monthly and comprised of 60% consumers, the consortia had formal by-laws and made policy decisions on the nature and type of services provided.

Strong and constructive links with the health department often led to other partnerships including a diversity of linkages with both public and private sector agencies. Pittsburgh Healthy Start, for example, while the first Healthy Start program to form a nonprofit, had continued its close relationship with the county health department, and had on

its board such community players as representatives of a community health center and the Port Authority. Some of the best examples of well-functioning community involvement were found in sites with strong community structures in place prior to Healthy Start. When Healthy Start was built upon an existing foundation in which there was perceived sensitivity and commitment to community issues, increased community engagement and sustained involvement were evident.

Being viewed as a valued resource to the community contributes to Healthy Start's sustained community involvement. The ability to maintain positive relationships with respected political leaders and having the support of local media increased the community's perception of Healthy Start as playing a leadership role in the community and delivering key contributions to overall community health. Because of their early requirements of implementing significant public information campaigns, most Healthy Start Programs had maintained strong relationships with local media. They had invited local newscasters to participate in special events and several media representatives regularly called Healthy Start programs when stories related to infant mortality, low birth weight or teen pregnancy were covered.

Access to key political leaders by Healthy Start programs created opportunities for moving the Healthy Start agenda forward and for obtaining key endorsements. In Cleveland and New Orleans, the mayors were strong partners in their cities' Healthy Start programs. Kansas City had strong political ties in both states where its programs are located—Kansas and Missouri. Its consortium's legislative committee was successful in convening consistent meetings reflective of this high level of participation.

Adequate resource base

Adequate resources to meet the needs of active community involvement are critical. Healthy Start's well-funded programs, especially in the beginning phase, created opportunities to implement approaches not usually associated with infant mortality reduction programs. Most administrators mentioned the early availability of flexible dollars as being key to accomplishing their goals, especially related to the major impact expected (50% reduction in five years). None of the programs felt the funds spent on consortia development and other community involvement strategies were excessive. Many directors reported that the money was well spent and that community involvement in turn generated more resources for the program. Interestingly, eight project directors had similar responses to the question on fiscal impact of consortia. While consortia support and consortia activities constituted significant line items in their budget, project directors saw the investment as critical to their mission, and as Philadelphia's director noted, "expensive, but worth it in the long run." Three programs commented that although it was initially very expensive, they were able to tailor their consortia component to maintain basic, though critical consortia activities. However, as mentioned earlier, a few programs noted that cuts in consortia staffing and related activities did have a negative effect.

Adequate resources to meet the needs of active community involvement are critical.

Incentives for participation

Like the existence of broad institutional support, a wide variety of incentives or inducements to participation also appeared to constitute important conditions facilitating community involvement. For Healthy Start consumers, incentives such as transportation and childcare (or reimbursement for childcare) often directly mitigated against some of the major barriers to involvement in consortia and other activities. Although particularly acute in rural Pee Dee, where the lack of any public transportation made vans critical to participation in the program, transportation assistance proved a major incentive in most of the nine sites.

Provision of meals and other tangible inducements also constituted important incentives for community involvement, though several focus group participants were quick to point out that food was not the main thing sustaining their participation. Rather, the receipt of education and training, the development of new skills, feeling listened to, and having a direct role in setting the program or meeting agenda were among the major incentives mentioned.

Focused, well-planned, and consistent outreach activities targeting program participants and community members surfaced as another factor that contributed greatly to increased involvement. Although taking different forms at different Healthy Start sites, having the program visible in the community through the use of lay health workers, the involvement of local churches and other valued local institutions was described by many as critical to sustained community involvement.

Using participant consortia members to reach out more broadly in neighborhoods was mentioned as a successful approach for outreach. A New York City participant offered an interesting solution to those consortia members who are inconsistent in meeting attendance, “You’ve got some devoted clients,” she said. “Ask us to help...we can do a little follow-up, send [them] a note saying ‘we missed you at the meeting’...We can do a little bit more.” When program directors and consortia leaders were asked what contributed to effective consortia, the responses included:

“A leader—a person who people listen to and feel comfortable with.”

“Address issues they have control over...They need to see small successes.”

“Connect what we’re doing and how it relates to them...Acknowledge them in infant mortality rates being reduced...People are suspicious of data and where it’s going. Break it down for them.”

“Both the MCH Director and Health Commissioner are pro-community advocates.”

“There is a constant level of work to keeping people engaged...it requires constant nurturing and developing [of] relationships.”

Although this analysis focused primarily on incentives to the participation of program participants and other community members, it was also important to consider how those inducements appeared to contribute to active and sustained involvement by providers. Incentives for providers clearly included the possibility of funding. Staff at several sites noted that as funds were cut, some providers ceased attending consortia meetings. For many others, however, a real belief in the importance of the program, networking opportunities, and the perceived chance to have real input in decision-making were key incentives to both initial and sustained participation.

Table 2	Contributors to Well-Functioning Consortia and Community Involvement Efforts
	<p>Broad institutional support</p> <ul style="list-style-type: none"> • Strong constructive links with Health Departments, which in turn lead to other partnerships • Strong links with a diversity of public and private agencies • Support from local political leaders and the mass media
	<p>Incentives for participation</p> <p><i>Consumer incentives</i></p> <ul style="list-style-type: none"> • Provision of enabling services (e.g., transportation and child care) • Receipt of education and training; development of new skills • Active engagement of churches and other respected community institutions • Visibility & active engagement of Healthy Start staff & outreach workers in the community • Perception of consumer meetings as “a place to come and talk and relax” • Provision of incentives (e.g., meals, cultural events, etc.) to enhance attendance • Generalized belief that reducing infant mortality is an important goal • Feeling listened to and knowing that community issues are taken seriously • Celebration of successes, e.g., through leadership training, graduation ceremonies <p><i>Incentives for community partners</i></p> <ul style="list-style-type: none"> • Possibility of funding contracts for service provision • Networking opportunities • Opportunities for churches and other partners to expand own base of support • Committee structures enabling participants to work on issues of special interest
	<p>Identification with the program and its mission</p> <ul style="list-style-type: none"> • Belief in the importance of Healthy Start’s goal of reducing infant mortality on the part of neighborhood residents, community agencies, and potential partners • Ability of program staff to elicit feelings of community buy-in and ownership of the program • Ability to put infant mortality reduction “on the radar screen” by connecting it to issues of greater immediate concern to community residents (housing, etc.) • Creation of nonprofit agencies (both a reflection of and a contributor to program identification)

Identification with the program and its mission

For both providers and community members, belief in the importance of Healthy Start's goal of reducing infant mortality was a major factor contributing to community involvement in the program. In Boston, regular presentations at consortium meetings included providing participants and other attendees with the actual numbers of infant deaths, women lacking access to prenatal care, etc. This information helped encourage belief in the importance of the program's mission. In other sites, such as Pee Dee, linking infant mortality with other issues, such as housing and substance abuse, which were of more immediate concern to residents, was part of "doing whatever it takes" to get infant mortality "on the radar screen." As a result of such efforts, according to Pee Dee's project director, there was "a tremendous amount of interest" in Healthy Start and a real change in the community's orientation to health outcomes.

The ability of program staff to elicit feelings of buy-in and community ownership of Healthy Start and its goal of infant mortality reduction also was described at many sites as a major contributor to well-functioning community involvement. In Boston and New Orleans, participants complimented the

program on soliciting ideas from the consortia and translating them into concrete programs. One young mother reported that, "You get an opportunity to express the kinds of changes you'd like, and what's working and what's not." One New York focus group member reported how proud she was upon reading in *The New York Times* a story about their Brooklyn site and recent reductions in New York City's infant mortality rates, "It makes me proud to know that what we are doing is working! There are less drug babies, more healthy babies, more people using condoms, decreased pregnancy rates...Our program is making a difference!"¹⁸

Finally, the creation of nonprofit agencies at many of the Healthy Start sites was both a reflection of, and a contributor to, identification with the program and its mission.

In sum, a variety of conditions appeared to provide fertile ground for well-functioning consortia and other community involvement activities. Laying careful groundwork by building trust, paying attention to community needs and issues and in other ways creating a real sense of ownership appeared to be critical. Table 2 (page 38) provides a concise summary of this diverse but interrelated group of factors facilitating community involvement in Healthy Start consortia and related activities.



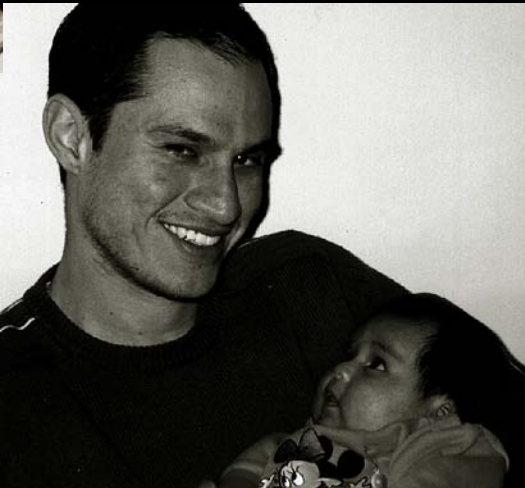
| Participants form crucial support networks through their attendance at consortium meetings.



From left to right: | Young women at Chicago consumer conference review pamphlets on prenatal care and parenting.
| Listening to the concerns of diverse participants helps programs develop unique ways of addressing race issues in health care delivery.

Conclusions

The PolicyLink study reveals that community involvement results in improvements to health and community outcomes.



Conclusions

The federal mandate to initiate community-based consortia as part of the Healthy Start Program served as a key catalyst and contributor for community involvement in program planning, implementation, outreach and success. This study determined the conditions that fostered well-functioning consortia and other community involvement strategies, as well as the conditions that posed challenges to such involvement.

The study demonstrated the broad range of contributions to Healthy Start program objectives that resulted from community involvement. This included providing significant aid and guidance in the quest to change individual behaviors and help participants be better parents, to the more macro level building of community capacity and mobilizing communities to push for changes in program policies and practices. The results of this study provide lessons for use in other public health and social programs seeking to involve community in program planning and implementation.

Healthy Start communities discovered that as community members participated in program activities and developed consistent relationships with Healthy Start workers, significant changes in behavior were often sparked: relationships with family members improved, new parenting practices were adopted, and behaviors or patterns that could result

in poor health outcomes were reduced. Heightened self-esteem frequently resulted from participants' increased sense of mastery over their personal lives and in their ability to change some of the environmental conditions impacting their daily lives. Many participants were motivated to become more involved in issues and activities in their communities, often leading to increased leadership roles and heightened civic participation.

All sites reported many benefits obtained through community participation, including the accomplishment of major program goals. Despite the many challenges faced by involving community members in program planning and implementation, Healthy Start administrators and consortia leaders agreed that sustained community involvement:

- *Increased awareness of and attention to infant mortality issues;*
- *Provided outreach to hard-to-reach populations;*
- *Developed individual skills and increased problem solving abilities;*
- *Contributed to the accomplishment of program goals;*
- *Pushed programs to address issues of importance to the community;*
- *Addressed critical issues of diversity related to race and class;*
- *Created significant partnerships with commitments to be sustained beyond Healthy Start's funding cycle;*
- *Created new infrastructure and enhanced communities' ability to address community problems; and*
- *Institutionalized community involvement strategies and changes prompted by it into programs, policies and practices in nonprofit and public sector agencies.*

Before Healthy Start, the problems of poor infant and maternal outcomes were not generally perceived as community problems and the link between individual behaviors and infant deaths was not well understood in many communities. Healthy Start increased awareness about infant mortality and mobilized communities to become involved in creating effective strategies to address the problem. The use of outreach workers and grassroots organizations as partners proved to be effective in creating a liaison between Healthy Start and the community and in initiating community organizing efforts that assisted programs in accomplishing their missions.

By actively engaging program participants, Healthy Start sites were able to reach target populations that traditional health care systems often had been unsuccessful in reaching. Word-of-mouth referrals proved to be especially important in communities lacking strong institutional relationships or those with histories of poor outcomes or mistrust of agencies and their programs. Many Healthy Start programs used neighborhood-based approaches or found creative ways to take services directly to high-risk populations: in jails, in mobile vans, in schools and in public housing units.

Through consortia trainings and workshops, program participants, providers and community members frequently were able to increase knowledge and skills concerning health (including breast feeding, diet, and child development), advocacy (in their personal lives and in program policies) and in job preparation and retention. Participants in some sites learned valuable self-sufficiency skills, leading to jobs and entrepreneurial ventures that decreased dependence on public assistance.

Community involvement in Healthy Start helped identify, prioritize, and address indirect causes of infant mortality, such as substance abuse, domestic violence, and lack of social support, homelessness, and unemployment. This facilitated feelings of ownership in the program and helped communities see the critical links between infant mortality and other pressing issues.

Healthy Start programs were able to adapt programs based on the racial, cultural, and linguistic needs of their communities. The consortia were a valuable mechanism for uncovering concerns related to race, class and language barriers. As a result, programs were able to address the complex diversity issues raised by demographic shifts and other neighborhood changes. Community involvement increased Healthy Start's ability to sensitively respond to their community's changing cultural landscape.

Healthy Start programs were able to adapt programs to fit the racial, cultural and linguistic needs of their communities. The consortia were a valuable mechanism for uncovering concerns related to race, class and language barriers.

Creating mutually beneficial partnerships with existing providers, community members and program participants led critical community stakeholders to value Healthy Start. Allowing community members and program participants to participate in program planning, implementation, and in some cases, high-level governance decision-making represented a new approach to community-based service delivery. Programs attracted additional community resources through this inclusive engagement of community.

Healthy Start programs and consortia were instrumental in increasing community empowerment and capacity building. Through the awarding of sub-contracts, hiring of community residents, inclusion of community leaders and providers, training of consortia members, and development of private non-profit organizations, Healthy Start assisted in building local infrastructure. All of the Healthy Start sites examined were able to institutionalize new programs, policies or practices as a result of community involvement. Through partnerships with health departments and other established community institutions, key components of Healthy Start were sustained following federal budget reductions.

The accomplishments highlighted in this report were not achieved without difficulty. Community involvement presented many challenges to Healthy Start programs. Some programs lacked sufficient experience in creating and sustaining consortia and

other community involvement mechanisms, particularly those lacking pre-existing coalitions or consortia. Programs needed to meet the challenges associated with: creating joint ownership of Healthy Start with the community, encouraging consistent participation, and developing the skills to manage tensions and conflicts.

Programs were challenged to motivate community residents to view infant mortality as an area of concern and to partner with Healthy Start in developing effective mechanisms to improve outcomes. Gaining community acceptance and engagement required concentrated effort, adequate resources, administrative support and time to build trust. Large grantee agencies and bureaucracies needed to adapt to sharing power with the community.

Major barriers had to be overcome in helping communities understand the need for and components of well-functioning consortia. Programs benefited from trainings in clarifying roles, decision-making, and problem-solving processes to assure optimum consortium development, functioning and maintenance. Leadership development, facilitation skills, communication skills, and organizational skills were needed to create structure and improve quality of consortia. A “culture of meeting attendance” needed to be developed and nurtured. Consistent attendance among providers and other partners also needed to be nurtured.

Some programs had considerable difficulty in maintaining an appropriate balance between providers, community members and participants as a result of racial, class or cultural differences; perceptions about power and money; or unresolved communication problems. Concrete efforts to address these issues helped the programs, providers, and participants better understand broader community challenges and changes.

In order for consortia and other community involvement efforts to succeed valuable members of the community had to feel welcomed by Healthy Start. Sincere mechanisms to actively engage program participants, respected community leaders and organizations needed to be ongoing and regularly assessed by key program and consortia leaders. Programs had to allow time to build relationships, develop consortia structures, remain open to receiving community input, and be willing to make needed changes.

Both Healthy Start programs and consortia benefited from participant feedback. Improved systems to solicit comments through satisfaction surveys, focus groups, or other feedback mechanisms

helped. To achieve meaningful community involvement, programs needed: community support and identification with the program and its mission, incentives for participation, an adequate resource base and broad organizational and institutional support.

Incentives for program participants, organizations and community members to attend consortia meetings included direct support in the form of childcare, transportation, and food to less direct benefits such as trainings, new skills development, and feeling part of a supportive community network.

To function well, consortia needed adequate funding and dedicated personnel. Healthy Start’s provision of discretionary funds allowed programs an opportunity to try unique approaches in obtaining community involvement. Using outreach workers, hiring participants, creating new positions that supported consortia development, and working with grassroots organizations—all these strategies assisted in establishing a sense of partnership with the community.

Healthy Start programs were successful in finding ways to sustain community involvement and consortia activities even when confronted with many challenges. All programs expressed openness to consistent involvement and found creative ways to integrate valuable community contributions.

The development of strong consortia—focused on addressing community issues, increasing awareness about infant mortality, linking important partners, developing comprehensive, creative strategies and working in partnership with the community—*did* make a difference in Healthy Start programs’ ability to create the conditions and build the infrastructure that can lead to improved health outcomes.



From left to right: | Effective delivery of services to culturally diverse families requires specific analysis of health indicators by race and ethnic community. | Cleveland mother (right) said this elder outreach worker offered her support “like family.” | Participants at consortia meetings reflect the hallmark of Healthy Start—they translate community concerns into effective program solutions.

Policy Recommendations

Community involvement can play a specific role in analyzing racial and ethnic disparity in health outcomes and engaging community institutions to address the problems.



Policy Recommendations

Community involvement resulted in clear and strong gains for Healthy Start programs and participants. In particular, community involvement was a key factor in programs' development of comprehensive services that were well targeted to clients' and communities' needs.

The future of Healthy Start is under debate. As Congress and the administration face major choices, they should ensure that their decision will sustain community involvement as a mandated program component. Without this mandate, one of the vital ingredients of the program could easily be lost, and with it, many of Healthy Start's successes.

The clear path to ensuring continued community involvement is maintaining Healthy Start as a separate program. Without specific language to develop new mechanisms and mandates, block granting the program to the states as part of Maternal and Child Health Services Title V Block Grant Program could result in the loss of programs and their community involvement components.

As part of their review, Congress and the administration should consider including similar community involvement mandates in the program requirements of other health service delivery initiatives.

To ensure meaningful sustained community involvement, future policy guidance and program mandates should require programs to:

1. Initiate and maintain active, substantive community consortia to participate in the building of integrated health delivery systems.
 - Roles for consortia should include:
 - Identification of community concerns;
 - Strategic planning that addresses identified concerns;
 - Identification and recruitment of community institutions to partner in implementation; and
 - Ongoing outreach, monitoring, program development and evaluation.
 - Support for consortia should include:
 - High-level administrative personnel to support the operation of consortia;
 - Clear guidance and access to technical assistance (including peer mentoring) in the development, governance structure, functioning and sustaining of consortia; and
 - Ongoing training for consortia members and leaders in governance, outreach, program evaluation, leadership and advocacy skills.
2. Focus communities on transforming programs, policies and practices (rather than focusing *only* on individual behavior) by requiring:
 - Geographic mapping of factors in the community that negatively impact health;
 - Analysis of mapping by diverse community stakeholders;
 - Identification of community institutions that can address priority factors; and
 - Community accountability for specific and realistic annual targets for reduction of negative factors.
3. Specifically analyze and develop plans to address racial disparity in health outcomes. Plans and implementation should address:
 - Cultural competency of health care providers;
 - Ability to reach target population with services;
 - Specific analysis of health indicators by race and ethnic community; and
 - Interventions that address specific racial and ethnic disparities.
4. Require linkage with other programs that provide life-long continuity of care and wrap-around services. For example, Healthy Start should either be linked with Early Start or expand its service delivery model to cover the time period from pregnancy to three years of age, when Head Start Services would be available to families.

All of the practices learned by Healthy Start programs about how to effectively involve community members in program planning and implementation should be continued, expanded and replicated to ensure that the many advantages are spread throughout the country's health care services delivery system.

For copies of 78-page full report or 16-page summary document, contact PolicyLink, 101 Broadway, Oakland, CA 94607, 510-663-2333, info@policylink.org, www.policylink.org



| Community involvement thrives when encouraged and celebrated.

Appendix A: Study Concept

Background

The project described below represents the first effort of PolicyLink to apply its expertise to the interface between formal health programs and the creation of healthy communities. A new national organization concerned with helping to connect local community building and national public policy, PolicyLink is particularly interested in Healthy Start because of the heavy accent that this ambitious national effort to reduce infant mortality has placed on community involvement strategies as an integral program component.

The project described below reflects our belief that, in addition to the excellent work already completed in the eight years of the program's operation, there is room for even more exploration in the critical area of community involvement. Within this key domain, we are committed to exploring and helping to carry forward the lessons of the Healthy Start experience for new Healthy Start sites, for the program as a whole, and for other health and social programs.

As a new national organization without government affiliation or funding, and with a diverse staff concerned with helping local community building efforts inform public policy, PolicyLink is in an excellent position to undertake this effort. Our project attempts to build on and complement, rather than duplicate, earlier work through a thoughtful exploration of community involvement at a selected group of Healthy Start sites. Based on the findings of this exploration, and the prior expertise of both its founder and its senior fellow in the history and evolution of Healthy Start, PolicyLink should be well positioned to tease out and share the lessons learned with a variety of stakeholders.

Statement of Purpose

As suggested above, the goal of this project is to further explore and carry forward the lessons of Healthy Start in the critical area of community involvement. With the guidance of a national advisory committee, we will examine, in nine carefully selected Healthy Start sites, the role of community involvement in program development and implementation, as well as site-specific experiences with achieving sustained and substantive community participation over time. Changes in the areas of program, policy and practice that may be related in part to each site's community involvement philosophy and strategies, will be identified and examined, and themes across the different sites surfaced and elucidated. Sites selected include: Boston, Pittsburgh, Kansas City, Cleveland, New York City, Chicago, Philadelphia, New Orleans, and Pee Dee, South Carolina.

In addition to the benefit that it should provide Healthy Start and those constituencies interested in learning from the Healthy Start experience, the proposed project will help PolicyLink further articulate a model for undertaking its own subsequent work in exploring and promoting community driven public policy.

Assumptions

Several key assumptions underlie the proposed project:

- A. The role of community involvement in Healthy Start, through consortia and other means, is a pivotal one worthy of more thorough exploration.
- B. A number of markers of effective community involvement can be identified.
- C. Community involvement includes, but goes well beyond, participation in formal consortia arrangements.
- D. Lessons from the Healthy Start experience with community involvement as an integral program component will benefit other health and social programs.
- E. A multi-site exploration of a sample of the original Healthy Start sites will provide valuable lessons about sustaining community involvement over time.

Research questions

1. What is the nature and functioning of the community involvement component at each Healthy Start site examined?
2. What conditions and processes contribute to well-functioning consortia and other community involvement efforts? What barriers and obstacles impede such functioning?
3. How do Healthy Start directors, consortia chairs and other key informants at each site view the community involvement component of the program and judge its quality and relationship to outcomes?
4. Did the community involvement component of Healthy Start result in or contribute to systems or community changes such as new or modified programs, policies or practices? If so, what were the changes or modifications (nature, intensity and duration of change and conditions under which it occurred)? In what specific ways were the consortia or other community involvement approaches involved?
5. In cases where there was a change in a health outcome (e.g., low birth weight or infant mortality rates), is there any evidence that there was a corresponding environmental change (e.g., a community or systems level change) that may have contributed to this? If an environmental change occurred other than any discussed in relation to question number three above, what role, if any, did the community involvement component of Healthy Start play in achieving this change?

Timeline

May-July, 1999

Initial project conceptualization and literature review.

July, 1999

Meeting with national Healthy Start program office and consultants, evaluation team members, and the Healthy Start Association to share and receive feedback on proposal.

July-September, 1999

Solicitation and incorporation of additional input on proposal; pre-testing of draft questionnaire in Oakland; first site visit.

September, 1999

Final revision of questionnaire based on pre-test, initial site visit, and additional feedback from Healthy Start evaluators and others; site visits.

September-October, 1999

Site visits; first advisory committee meeting in New York.

November-December, 1999

Completion of site visits.

January-March, 2000

Transcribing and data analysis; beginning preparation of policy briefs, monograph, articles for publication and other products.

March-June, 2000

Second advisory committee meeting.
Completion and dissemination of Healthy Start project monograph and other products.

Appendix B: Overview of Methods and Analysis

A multi-site case study design was identified as the best method for addressing the project's research questions. This approach also was selected in recognition of the fact that while we anticipated finding some important commonalities across sites, each Healthy Start program examined would have specific contexts, conditions and processes of change that would require in-depth exploration as we focused in on the area of community involvement.

Site selection

Site selection for this study was based on conceptual rather than representational grounds in order to address our research questions and working hypotheses. We had originally planned to select five to seven sites on the basis of a number of criteria. We wished to include, for example, both urban and rural sites; sites with varying levels of achievement of health outcome objectives; sites that had impacted on policy or showed potential for doing so in the future; and sites that were sources of positive lessons from the Healthy Start experience as well as illustrative of barriers, tensions and areas for improvement. It was decided that nine sites met all of our criteria and would add a breadth and diversity of experience that warranted expanding our intend-

ed sample size. The final sites chosen were: Chicago, Boston, Cleveland, Philadelphia, Pittsburgh, New Orleans, New York City, Kansas City and Pee Dee, South Carolina.

Data collection

Each site was visited over a two-day period by the Project Director and one to three other members of the PolicyLink team. Site visits included key informant interviews, observation of relevant meetings and programs, collection of project newsletters or other pertinent written material, and a follow-up focus group with program participants, community members and providers.

Interview schedule/questions

At the heart of our data collection were key informant interviews with two or more of the major actors at each program site. A standardized semi-structured questionnaire was developed by the Project Director and consultant to obtain an in-depth look at community involvement at each HS site selected while also enabling comparisons across sites. The original instrument of more than 40 items was pre-tested in a non-participating Healthy Start site (Oakland), and modified based on the pre-tests. Further input from the Advisory Committee, consultants at the national Healthy Start office, and the Project Director's early experiences with the original instrument led to further revisions and refinements. The final instrument included 28 questions, several with a number of sub-parts, under four sub-headings: consortia, processes of community involvement beyond consortia, outcomes, and sustainability related to consortia.

Key informant interviews

To facilitate comparability of data across sites, the visiting team tried to interview comparable individuals at each site including, at minimum, the current project director and consortium chair. Respondents each participated in a formal interview based on the 28-item interview schedule/questions (Appendix C, page 59) but also were encouraged to "tell their stories" both within and outside the interview process. The interviews were conducted on site, usually in the respondent's office, and typically took 60-90 minutes to administer. Although the two key respondents (director and chair) were often interviewed independently of one another to facilitate openness and an ability to compare responses, at several sites, joint interviews had to be conducted with other staff out of respect for their time constraints. All interviews were recorded with the permission of participants.

Informal meetings with additional staff

In addition to the key informant interviews discussed above, team members were given the opportunity at several sites to meet informally with outreach workers and/or other staff members. These informal sessions frequently included several individuals and incorporated questions from the formal interview schedule only to the extent appropriate for the parties concerned. These sessions also were tape recorded.

Focus groups with consumers, consortium members and providers

In response both to a suggestion from our Advisory Committee and the PolicyLink team's own perceived need to hear the voices of consumers more directly, a focus group component was added to the study at each site. An eight-item focus group instrument (see Appendix D, page 63) was developed by the Project Director and consultant with considerable input from the Advisory Committee, and was used by a member of the PolicyLink team with a group of four to nine Healthy Start consortium members. Group participants were volunteers identified by the consortium chair or a Healthy Start staff member, and each received a \$50 honorarium for his or her participation. Participants typically had had some active involvement with the consortium and/or a sub-committee of the consortium at their site. The focus group, which was held subsequent to the rest of the site visit, typically ranged from 45 minutes to an hour-and-a-half.

Observations

To the extent possible at each site, visits were scheduled so that participating team members could observe a consortium meeting or sub-committee meeting, attend other relevant events, and visit family life centers and/or other key program components.

Document collection

An attempt was made to collect from each site written data in the form of newsletters, recent reports or other documents that might capture additional insights about the community involvement component of the project.

Background data

Finally, our data collection included the gathering of a wealth of pre-existing administrative and evaluative data on each Healthy Start site in the study from both the Healthy Start Association and the National Office. To avoid contaminating our analysis of site visit interview and observational data, these background materials typically were not reviewed until completion of the primary data analysis. They subsequently were used, however, to help us situate our findings in a broader historical context.

Data management and analysis

Following each site visit, the Project Director developed a brief (one page) overview summarizing key findings under nine headings: fiscal agent, consortia, committees, structure, governance, program, unique feature, outcomes and key quotes (see Appendix F, page 67). In addition to this form, which provided very useful standardized information across each of the sites visited, PolicyLink team members at each site visit wrote up their initial impressions, ideally within a week of the visit to preclude the loss of valuable "first impressions" data and observations. Audio tapes from each interview and focus group were transcribed verbatim by a professional transcriber.

The Project Director, consultant and a doctoral student working with the consultant then each reviewed the transcripts independently by site to (1) identify findings that helped address the project's research questions and working hypotheses and (2) identify emerging themes within each site whether or not these were directly related to the research questions. The latter process enabled us to take full advantage of the qualitative nature of the data by remaining open to new insights and findings that, although not originally tapped through either the working hypotheses or the research questions, may provide new avenues for understanding the community involvement component of Healthy Start.

As is often the case in multi-site studies, there was considerable variability between sites both in terms of the nature and extent of data gathering that was possible, and the applicability of portions of the main data gathering instrument in terms of their ability to capture the essence of the site under investigation. In lieu of a more formalized coding template, therefore, the three individuals reviewed transcripts and observational notes for themes that emerged both related and unrelated to the research questions under study. Themes originally identified were listed as marginal notes directly on the transcripts of each investigator. Themes that appeared across several questions (e. g., community capacity building and barriers to the perceived effective functioning of the consortium) were then grouped together to facilitate more detailed exploration.

Following completion of independent thematic analysis by site and the synthesis of key findings, each investigator looked for patterns and themes across sites. These included, for example, whether certain program models, types of sponsorship, or levels of staff or consumer diversity were associated with particular community involvement outcomes, whether there were any “universal truths” or lessons learned across sites, and what the outlier sites were with respect to given themes. Each of the three persons involved in data analysis independently identified the major themes that emerged from her cross-site data analysis. Both the analysts’ individual thematic analyses by site and their cross-site themes then were compared to assess the degree of correspondence or agreement on theme and sub-theme identification. A final set of themes across sites then was developed and was incorporated into the site specific and multi-site case studies, and throughout this present report.

Appendix C: Interview Schedule/Questions

The following interview questions were asked of project directors and consortia chairs at study sites.

1. Please start out by telling me a little about yourself and your role in Healthy Start. (Probe, if appropriate, whether interviewee was ever a Healthy Start client.)
2. How does your Healthy Start program define or think about community? (Probe: geographic? other?) How do you think about or define community involvement?

Consortia

3. Please tell me a little about your consortium: types of members, frequency of meetings, roles, etc. How are members selected?
4. What types of members currently attend? (Approximate number or percentage of providers, consumers, agency representatives, etc.)
5. Please describe the agenda of typical consortium meetings. (Probe: information sharing? problem solving?) If the consortium has different committees, please describe the ones you are most familiar with.
6. Some Healthy Start sites report difficulty in getting and sustaining participation of community based organizations or consumers in their consortia beyond small levels of involvement. What

has your experience been with getting participation? With sustaining participation? What is the average length of time community members serve?

7. Does the membership of the consortium reflect the racial/ethnic make up of the community? Does it also reflect the community's social class make up? What about the composition of the Healthy Start staff?
8. Has there been consistency or lack of consistency in who attends meetings? Has this impacted decision-making or group functioning? (Probe for examples.) In the last three months, have there been any new members?
9. In your experience, what are the most effective size and composition of a consortium? For example, does it seem to work best to have a few consumers or many? Lots of agencies represented, or just a core group?
10. What factors seem to contribute to keeping the consortium going and working well? Were there factors that got in the way of its functioning well?
11. Are consortium members asked by consortium leaders or project staff for their feedback from time to time on how the consortium is working? On other aspects of the Healthy Start program? (Probe for examples and whether any changes were made based on the feedback.)
12. At what stage did the consortium seem to work best (e.g., needs assessment, outreach or program planning)? Least well? Please describe.

Outcomes/sustainability related to consortia

13. Has the consortium addressed community issues that transcend the primary concerns of the program? (If appropriate, probe what issue(s) was addressed. What was done? Any results?)
14. Are there any community programs or services in place that started out as an idea of the consortium? (If so, please describe.)
15. If Healthy Start involved the development of a new consortium, do you think, in retrospect, that this was a good idea or would it have been better to work through a preexisting network or coalition?
16. Has any aspect of the Healthy Start program been integrated into the Health Department or other agency? Institutionalized in other ways? If so, did the consortium activities have a role in helping make this happen? (Please describe.)
17. Looking back, did the program's consortium appear to help in achieving project goals and outcomes? Did it create problems? (Probe examples.)
18. Would anything have been lost if there were no community involvement component in Healthy Start? Would there have been any advantages to not having as much community involvement? (Probe.)
19. What has been the fiscal impact of creating and maintaining an active consortium? (Probe costs and money that may have been brought in as a result of the consortia.) Are there staff devoted full or part-time to community involvement? (Probe for changes over time.)

Process of community involvement
beyond consortia

- 20. Beyond consortia, in what other capacities have community members been involved?
- 21. Were community members trained for their roles in the project? In paid or volunteer capacities? Were there opportunities for upward mobility? (Probe examples.)

Outcomes

- 22. Did Healthy Start change the community's orientation to health outcomes? If so, did the consortium or community involvement component seem to play a role in this? (Probe: If yes, how important was this role?)
- 23. I'd like to ask, now, about a number of possible outcomes and side effects of community involvement, both positive and negative. Did the community involvement component of Healthy Start result in:
 - a. Changes in the level of integration of prenatal or pediatric services? If so, when? Please describe.
 - b. Other new or modified programs? (If so, when? Please tell me a story.)
 - c. New or modified practices? (If yes, when? Tell me about it.)
 - d. New or modified policy? (If yes, when? Please describe.)
 - e. Tensions between ambitious program goals and the requirement that consumers be actively involved?
 - f. Competition with pre-existing agencies or coalitions for funding or membership?
 - g. Contributions to community revitalization?
- 24. Some Healthy Start sites have reported tensions based on race, class or professional hierarchy. What has been your experience?
- 25. Did you find it was easier to bring to the surface and talk about issues of race, or class, because of the nature of the group? Was it harder? Were things dealt with differently because of this?

26. Did those hired by Healthy Start go on to get other jobs in or outside the community? Do you have any figures or examples of this? (If you don't know, is there someone who would have this information, e.g., a former director or staff member?)
27. Please describe a situation that made you aware that things are different now in terms of community involvement in Healthy Start (e.g., how your consortium handles things now versus in earlier days). Can you think of any other critical event that occurred? What were the conditions under which it took place?
28. If you could advise a new Healthy Start director on how to get and sustain involvement of the community, what might you say? Any lessons you'd like to pass along?

Appendix D: Focus Group Questions

The following interview questions were asked of focus groups of consortia members, including program participants, community leaders and providers at each study site.

These questions were asked of focus groups consisting of program participants and consortia leaders at each study site.

1. How long have you been involved with Healthy Start as a client? As a consortium member? Please tell me a little about how you got involved and the extent of your involvement.
2. Did you receive any training in relation to this role?
3. Has the consortium addressed issues that matter to you? Are there other issues it should address? (Probe for obstacles encountered along the way and what was done to address them.)
4. Do you feel the consortium is working well? Why or why not? What could be done to make it work better? (Probe for obstacles encountered along the way and what was done to address them.)

5. Have you been asked for your ideas on how to make the consortium run more smoothly? Is there anything you'd like to see tried?
6. Have there been changes in you, your family or your community as a result of your being a Healthy Start client? If so, what has changed?
7. Have there been changes in you, your family or your community as a result of your being a member of the consortium? If so, what has changed?
8. What's the most important thing that's happened in this Healthy Start program since you became a client? (Probe: was the consortium or other community involvement a part of it?)

Appendix E: Advisory Board Members

Alayne Adams, Ph.D. is Assistant Professor of the Mailman School of Public Health at Columbia University.

Clair Brindis, Ph.D. is Adjunct Professor of Pediatrics of the Division of Adolescent Medicine's Department of Pediatrics for the University of California, San Francisco.

Elize Brown, J.D. is a Program Officer for the Robert Wood Johnson Foundation.

Grace Carroll, Ph.D. is Senior Research Associate with the Capstone Institute and Center for Research on the Education of Students Placed at Risk at Howard University.

Maria Casey is Executive Director of the Partnership for the Public's Health.

Barbara Kelley Duncan is Vice President of Leadership Development and the Black Community Crusade for Children for the Children's Defense Fund.

Linda Edgeson is Chicago's Healthy Start Consumer Representative.

Steve Fawcett, Ph.D. is Kansas Health Foundation Professor of Community Leadership and Distinguished Professor of Human Development for the University of Kansas.

Diane Foster is Kansas City's Healthy Start Consumer Representative.

Jackie Gillon is Cleveland's Healthy Start Consortia Representative.

Vicky Jacobs is Pee Dee's Healthy Start Consumer Representative.

Otis Johnson, Ph.D. is Dean of the College of Liberal Arts and Social Sciences for Savannah State University.

Thurma McCann Goldman, M.D., former federal Healthy Start Director, is a Pediatrician and Chief of the Division of Health Systems Management in the Health and Safety Directorate for the United States Coast Guard.

Kelly McNally-Koney, MSSA is a Consultant and Researcher in North Carolina.

Belinda Pettiford, M.P.H. is Program Manager for the Healthy Start Baby Love Plus Initiatives of the Division of Public Health in South Carolina. She serves as the Healthy Start Association Representative.

Melanie Tervalon, M.D. is a pediatrician and Assistant Professor at the University of California, San Francisco.

Juan Sepulveda is the President of The Common Enterprise in San Antonio, Texas.

Appendix F: Site Summaries

Pittsburgh Healthy Start

Philadelphia Healthy Start

Boston Healthy Start

Chicago Healthy Start

Kansas City Healthy Start

Cleveland Healthy Family/Healthy Start

Pee Dee Healthy Start

New Orleans Healthy Start
(Great Expectations Foundation)

New York City Healthy Start

Pittsburgh Healthy Start

- Site Visit: August 26-27, 1999
- Interviewers: Mildred Thompson, Janet Bell and Kalima Rose
- Fiscal Agent: Allegheny County Health Department
- Consortia:
 - Regional Consortia Model: each of six areas has consortium with 18-25 members
 - Representatives from each consortium on Board of Directors
 - Strong consumer participation
 - Full consortia of 120 members
- Structure:
 - Regional consortia meet bi-monthly
 - Formal Policies and Procedures manual
- Governance:
 - Consortia makes policy decisions on type and level of services
 - Input on budget and personnel decisions
 - Participants active in federal application process, evaluations, approval of media campaigns and program planning
- Program:
 - Six service areas of city and county
 - Case management model
 - Drug and alcohol prevention
 - Male initiative program
- Unique Feature:
 - Consortia orientations held twice yearly
 - Specific membership guidelines: consumers, neighborhood organizations, ministers, business leaders, youth, elected officials and health providers.
 - Public housing has designated slots
 - Formal written evaluations of each consortia meeting
- Outcomes:
 - Forums on welfare reform
 - Extensive trainings
 - "House of Hope," a residential substance abuse program for women and their children
 - "Healthy Start House," a home for pregnant and postpartum women
 - More integrated, comprehensive service systems in place
- Key Quotes: Project Director:
"Don't promise what you can't deliver...If you don't value the community, don't take the job...be willing to listen, be respectful and be ready to do battle...lots of hard work. Healthy Start is not a program, but an ideology, a movement."

Philadelphia Healthy Start

- Site Visit: September 14-15, 1999
- Interviewers: Mildred Thompson and Rosia Blackwell-Lawrence
- Fiscal Agent: Philadelphia Department of Public Health, MCH
- Consortia:
 - Very strong consumer participation model, limited role by providers
 - Healthy Start funds consortia
 - Consortia Chair is a male community activist, involved for eight years
- Committees:
 - Collaboration
 - Public Awareness
 - Public Policy
 - Steering
 - Support Services
 - Sustainability
- Structure:
 - Committees meet monthly
 - Full consortium meets six times annually
 - Town meetings twice a year
 - 200 at last town meeting, including 50 men and teens
- Governance:
 - Consortia makes policy decisions on type and level of services
 - No budget or personnel decisions are made by consortia
 - Acts in advisory role on program planning
- Program:
 - Primarily outreach model with risk reduction and adolescent focus
- Unique Feature:
 - Healthy Start staff are not members of consortia and does not regularly attend meetings
 - Staff attends when agenda items require their presence and do not vote on issues
- Outcomes:
 - Healthy Start protocols and reporting systems now integrated into Title V Block Grant
 - Some services cut by Healthy Start due to budget cuts are now part of managed care
 - Many Healthy Start clients attended community college
- Key Quotes: Consortia Chair:
"We do more than give a hot dog and a bus token....We use Healthy Start as a tool to organize community issues."
- Healthy Start Administrator:
"...even with all the challenges, it's been worth it to work with the consortia...it was through them that we got the word out about infant mortality...the community was quiet before."

Boston Healthy Start

- Site Visit: September 21-22, 1999
- Interviewers: Mildred Thompson and Janet Bell
- Fiscal Agent: Boston Public Health Commission
- Consortia:
 - Very strong consumer-participation model
 - Seven communities, including Chinatown
 - Monthly meeting, 60-75 members on average
- Structure:
 - Consortium—60% consumers, 40% frontline staff from community-based organizations and hospitals with limited top administrators
 - Formal by-laws
 - Executive committee elected yearly
- Governance:
 - Consortia makes policy decisions on type and level of services
 - No budget or personnel decisions and cannot determine who receives funds
 - Significant influence on outreach strategies and marketing tools
- Program:
 - Case management, with strong home visitation component
- Unique Feature:
 - Federal Healthy Start uses Boston for consortia technical assistance for new cities
 - Strong leadership development training component, participants required to get involved with another community initiative after attending the training. Certificates awarded
- Outcomes:
 - Provided training and developed health centers in five public housing tenant associations
 - Within two years 40 women trained and hired as outreach workers throughout community
 - City of Boston uses their consumers for community input and focus groups
 - Healthy Start negotiated conditions for use of clients: payment for time, information on how input is to be used, and sharing of results
- Key Quotes: Director of Male Services:
"The STRIVE Program (job training) may help them to get a job, but we help them keep it."
- Healthy Start father, on why he attends the program:
"I come because I want to support my kid."
- Program Director, on lessons learned:
"Consider what your capacity is to include the community. Must learn how to distribute power, realistically. Must help fiscal agency in understanding value of community involvement."

Chicago Healthy Start

- Site Visit: September 30-October 1, 1999
- Interviewers: Mildred Thompson, Meredith Minkler and Heather Tamir
- Fiscal Agent: State of Illinois, Department of Human Services
Currently six separate programs in Illinois (four in Chicago)
- Consortia:
 - Very strong consumer participation model
 - Chair, Dr. W. Frazier, member of consortia eight years
- Committees:
 - Executive
 - Consumer Mobilization Data and Evaluation
 - Family Centered Services
- Structure:
 - Committees meet monthly
 - Full consortia meets quarterly and annually
 - 60-90 members at typical meeting
 - Consumers represent 40-60% of meetings
- Governance:
 - Consortia makes policy decisions on type and level of services
 - Consortia does not make budgetary or personnel decisions
- Program:
 - Five family centers and subcontractors
 - Each center has five consortia reps: three consumer and two administrative
- Unique Feature:
 - Last year, program hosted Consumer Conference; 250 consumers attended
 - With state as fiscal agent, easy to coordinate perinatal and pediatric services
- Outcomes:
 - Several previous clients have started businesses—catering, income tax service, and flower arrangement
 - Statewide data system, Cornerstone, was adapted from Healthy Start's MIS system
 - As result of opposition from consumer community, Medicaid Managed Care is not mandated
- Key Quotes: Chair, Consumer Mobilization Committee (on need for consumer involvement):
"You have to have a reason to serve and the reason is the babies. You have to have the involvement of the people. Any program that's ever been a failure failed because it did not include the people it served."

Kansas City Healthy Start

- Site Visit: October 13-14, 1999
- Interviewers: Mildred Thompson, Judith Bell, Zita Allen and Elize Brown
- Fiscal Agent: Heart of America United Way
- Consortia:
- Strong provider representation
 - Healthy Start funds consortia administration
 - Consortia Chair is Maternal and Child Health Coalition Executive Director
- Committees:
- Legislative
 - Pregnancy
 - Infant/Child
- Structure:
- Committees meet monthly
 - Full consortia meets quarterly
 - Still an evolving consortia; program is not one of original 15
 - Limited consumer participation
- Program:
- Case management, enhanced clinical services
 - Outreach, training and education
- Unique Feature:
- Program service area crosses two states: Kansas and Missouri
 - Strong involvement of political leaders from both states
- Outcomes:
- Program sponsored conference to increase awareness of needs of Hispanics
 - KC WAIT, focused on teen pregnancy prevention, now integrated at Institute for Human Development
- Key Quotes: Administrator for KCHS:
"Professionals realize they will not succeed unless they involve the community."
- Focus Group Member:
"What's important to me about the meetings [consortia] is just being in the group, talking about my problems...It's been helpful to me."

Cleveland Healthy Family/Healthy Start

- Site Visit: October 26-27, 1999
- Interviewers: Mildred Thompson, Kalima Rose and Zita Allen
- Fiscal Agent: Cleveland Department of Public Health
- Consortia:
 - Eight sites, (primarily, “settlement houses”) serve 15 Healthy Start neighborhoods
 - Three clusters, composed of five neighborhoods, have a consortium that meets monthly. Yearly meeting of the project-wide consortium
- Committees:
 - Consortia Leadership Committee (CLC) meets quarterly. Each of the eight sites has a representative on this leadership committee.
 - Executive Council governs the project as a whole and is chaired by the Mayor. Meets quarterly.
 - Clinical / Social Committee meets monthly
- Structure:
 - Administered by a community agency, Neighborhood Centers Association.
 - Typically, 80% of members are community based and 5% providers.
 - Consumers must attend a minimum of 3 meetings to become an active consortia member.
- Governance:
 - Executive Council and Administrative Management Group makes policy decisions.
 - Management team, Administrative Management Group (AMG), meets every other month. Membership is composed of HS administrative staff and program managers from subcontractors.
 - Executive Council and AMG meet quarterly, and are also attended by CLC representatives. Consumers are not a part of this Council.
- Program:
 - Case management program
 - Case management and health education in correctional facilities
 - Mobile health clinic (MOMobile)
- Unique Feature:
 - Program for incarcerated women in correctional facilities
 - Some consortia members are seniors and some outreach workers are older than typical outreach workers
- Outcomes:
 - The Cleveland health department received funds from Ohio Department of Health to operate an Ohio Infant Mortality Reduction Initiative (OIMRI), which funds 10 OIMRI programs across the state.
 - Healthy Start’s outreach model replicated through this grant, which received city funds to serve four additional areas on the city’s near west side.
- Key Quotes: Consumers, Focus Group Session:
“Meetings really address issues that matter—car seats, immunization shots. You need to have this information. Everything I learned at these meetings mattered and was important.”

Pee Dee Healthy Start

- Site Visit: November 3-4, 1999
- Interviewers: Mildred Thompson and Heather Tamir
- Fiscal Agent: Private non-profit, program recently obtained 501(c)(3) status
- Consortia:
 - Three levels of consortia: one for consumers, one for providers (coalition), and one focused on males
 - Efforts are underway to combine provider and consumer groups
 - Consumers meet monthly, providers meet quarterly
 - Since program is responsible for six counties, spanning a 100 mile radius, with one staff person coordinating consortia efforts, recently a decision was made to focus on three counties.
- Structure:
 - Coalition members consist of Health Department, Social Services, schools and community health center representatives.
 - Currently, proportion of clients to providers is 70% consumer and 30% community members and providers.
 - Average attendance of consumer consortium is seven consumers, with a range of 3-20. The provider group is smaller.
- Governance:
 - The organization's board of directors makes governance decisions.
- Program:
 - Rural program that serves six counties is primarily an outreach model.
 - Rural Outreach Advocacy and Direct Services (ROADS) teams saturate communities to recruit and refer clients.
 - Male component educates fathers and potential fathers about infant mortality.
- Unique Feature:
 - Program created 501(c)(3), after terminating long-term relationship with United Way.
 - Accessibility to services is a challenge due to rural environment and isolation of the targeted area; lack of public transit systems
- Outcomes:
 - Continuation of ROADS Teams by Health Department and private nonprofit after Healthy Start funds were eliminated.
 - Fetal Infant Mortality Review (FIMR) also continued by Health Department.
- Key Quotes: Staff Person:
"Healthy Start is helping to empower people in rural counties. The need is so large that we are only touching the tip. Looking forward to branching out."
- Staff Person:
"Young people do not have dreams. Few role models here versus in urban areas. Need to create more opportunities for professionals. Pee Dee void of young talent."

New Orleans Healthy Start (Great Expectations Foundation)

- Site Visit: November 8-9, 1999
- Interviewers: Mildred Thompson, Kalima Rose and Heather Tamir
- Fiscal Agent: City of New Orleans, Mayor’s Office, receives Healthy Start funds; passes through to Great Expectations Foundation, a 501(c)(3)
- Consortia:
 - Ten target areas; each has Service Area Advisory Council (SAAC) that meets monthly and includes clients, providers, community activists, other agencies.
 - Yearly general consortia meetings including all 10 target areas.
 - Each SAAC sends one representative to the “Consortia Steering Committee,” which includes 10 SAAC representatives, the Great Expectations Executive Director, Consortium Coordinator, top administrative staff and five consumers.
 - Leadership council, composed of four representatives from SAAC, chairs committees of the consortia and sits on the board of Great Expectations Foundation.
- Committees:
 - Community Relations
 - Administrative and Finance
 - Economic Development
 - Program Services
 - Great Expectations Foundation’s board of 15 has eight seats appointed by mayor: three are Healthy Start consumers; four are consortia “leadership council” representatives; and, hospital appoints three seats.
- Structure:
 - 1999 Strategic Plan guides goals and objectives.
 - Formal consortium by-laws were recently amended and adopted.
- Governance:
 - Consortia Steering Committee makes recommendations on service delivery models, identifies community needs and partnerships.
 - Four leadership council and three consumer representatives make policy decisions on Great Expectations Foundation’s board of directors.
- Program:
 - Ten target areas served at three multi-service centers
 - Abstinence and Teen Pregnancy Programs at middle schools, high schools, in churches
 - Case management model
 - HIV/AIDS Case Management
- Unique Feature:
 - Administrator of nonprofit housing developer is Chair of Consortia.
 - Steering committee has committed community activists that bring strong resources in economic development.
- Outcomes:
 - Recently implemented use of MIS data from county, state, and federal sources to disaggregate indicators by target area; now each SAAC setting goals based on own indicators.
 - \$10,000 partner mini-grants awarded to community organizations.
- Key Quotes: Executive Director, GEF:

“The strategic planning marked the first time board members sat down with consumers and understood that their voice is just as important—an equality emerged that was noticeable.”
- Consortia Member:

“Being a member of the consortia has made me a more responsible parent.”

New York City Healthy Start

- Site Visit: March 1-2, 2000
- Interviewers: Mildred Thompson and Zita Allen
- Grantee: Medical and Health Research Association of NYC, Inc.
- Consortia:
 - Regional model. Three local area consortia (representing the program's three target areas of Harlem, Brooklyn and Bronx) and one city-wide consortium. Contracts awarded to community agencies to provide services and convene consortia.
 - Primary focus of this visit was the Harlem consortium, which is administered by Northern Manhattan Perinatal Partnership, Inc.
 - Representatives from each local consortium participate in city-wide consortium
- Committees: Citywide Consortium Committees
 - Management and Governance
 - Resource Development
 - Policy and Advocacy
 - Evaluation
 - Special Projects
Harlem Local Area Consortium Committees
 - Case Management
 - Advocacy
 - Public Relations
- Structure:
 - Management and governance committee meets monthly
 - Full citywide and local consortia meet quarterly
 - In citywide consortium (approx. 70 members), participants are mostly providers
 - In local consortia (approx. 25 members), participants are largely consumers and community members
- Program:
 - Case management
 - Consortia
- Unique Feature:
 - Regional consortia approach
 - Program is managed by private non-profit. Services are provided via contract by community-based perinatal networks and by the City Department of Health.
 - Large diverse populations, including increased numbers of Latinos, undocumented immigrants, Dominicans, French-speaking Africans.
- Outcomes:
 - Creation of Harlem Works, computer training center for consumers
 - Bronx Perinatal clinic at school for pregnant girls
 - Brooklyn, nurse midwifery program
 - Male involvement consortium
 - Head Start recently funded program at Harlem site
- Key Quotes: Program Director, Harlem site:

"We find that it is really hard to engage new mothers in the consortia. It's not really appropriate to expect them to come, with all their many needs....Maybe toward the end of their time with us, when the baby is older, we can involve them."

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