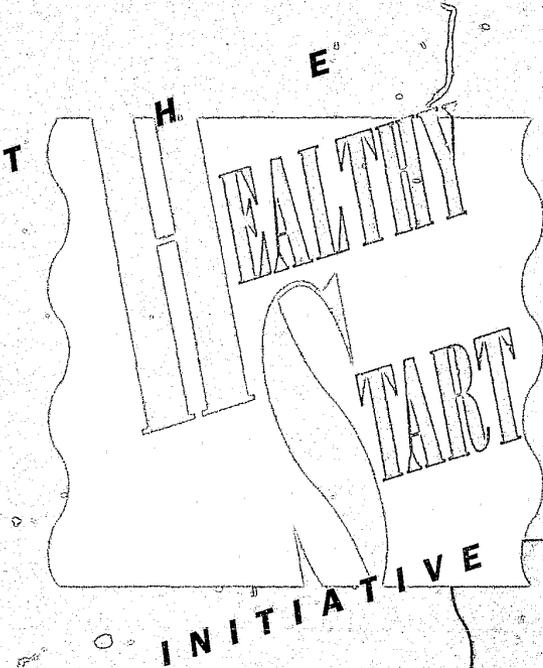
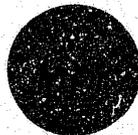


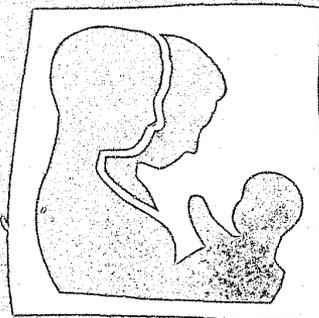
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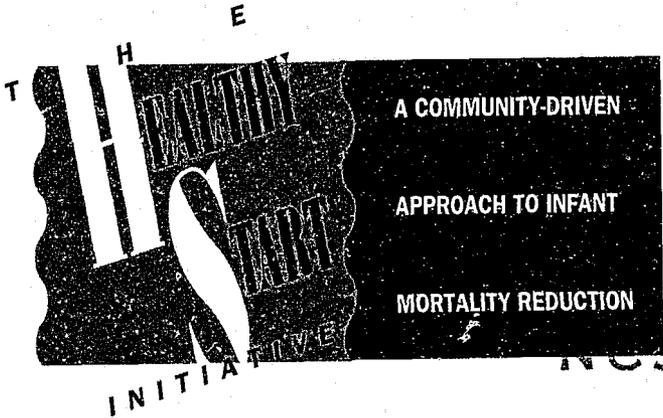
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# ***Consortia Development***

**Volume I**

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Volume I

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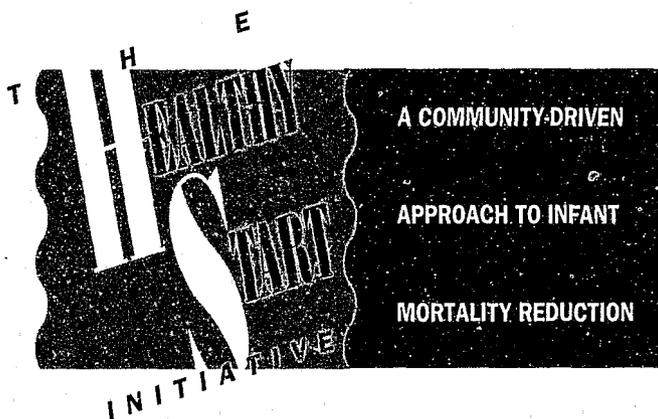
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**Volume I**

# **Consortia Development**

By Meri McCoy-Thompson, M.A.L.D.

National Center for Education in Maternal and Child Health

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## Foreword

The Healthy Start Initiative is a national five-year demonstration program which utilizes a community-driven, systems development approach to reduce infant mortality and improve the health and well-being of women, infants, children and families.

In 1991, the Department of Health and Human Services funded entities in 15 rural and urban project areas which had infant mortality rates that were 1.5 to 2.5 times the national average. These projects are implementing innovative approaches to develop coordinated, comprehensive, culturally competent models of health and other support services.

Because of the widespread interest in learning about Healthy Start and what the projects have done to effectively impact on infant mortality, this premiere publication, *Consortia Development*, is part of a planned multi-volume series *The Healthy Start Initiative: A Community-Driven Approach to Infant Mortality Reduction*. The series of publications will provide a mechanism by which current and critical information about the projects' activities can be shared and widely disseminated. Volume II of the series, *Early Implementation: Lessons Learned*, will be available in Spring 1994. Other volumes being considered for future publication include: *Early Outcomes*, *The Dos and Don'ts of One-Stop Shopping*, and *What Works*.

*Thurma McCann, M.D., M.P.H.*  
*Director*  
*Division of Health Start*  
*Maternal and Child Health Bureau*

## Preface

*"The children and families who participate in our education and human services systems are essential for its reinvention. They are indispensable partners with educators, human service professionals, business leaders, civic and religious leaders, leaders of community-based organizations, and other citizens in creating the profamily system."*

— Melaville, Blank, and Asayesh in *Together We Can: A Guide for Crafting a Profamily System of Education and Human Services*

Giving people a voice in the systems that affect their lives can be very powerful. When a community is able to redesign its health and social service systems, both the community and its systems are transformed. But community participation in reshaping systems does not just happen. If all members of a community are truly to have an impact on the system, they must have an organized voice. Collaborative efforts are becoming that voice. As Melaville, Blank, and Asayesh suggest, "By virtue of their broad based representations, collaboratives are an emerging force for change in America's communities."

As more communities try to change their health and social systems to make them responsive to their needs, collaborative efforts are becoming recognized as potent vehicles for transformation. The federal Healthy Start Initiative has recognized that potency and has placed collaboration at the center of its efforts. The purpose of the Healthy Start Initiative is to reduce infant mortality by helping communities assess their needs and decide which interventions work best. While the Initiative focuses on reducing infant mortality, its efforts to involve the community in collaboration can be replicated to tackle other public health problems. As health care reform attempts to alter the health and medical system in America, the benefit of collaboration becomes even more relevant: as a community transforms its systems to meet its needs, the community is empowered.



## Introduction

The purpose of the federal Healthy Start Initiative, a national demonstration program, is to reduce infant mortality by 50 percent in 15 communities. The federal Healthy Start Initiative is based on several principles:

- Innovation in service delivery;
- Community commitment to the goals and objectives of the Initiative;
- Personal responsibility demonstrated by expectant parents;
- Increased access to services and resources;
- Integration of a comprehensive package of health care and social services; and
- Multi-agency participation to facilitate incorporation of related programs into Healthy Start.

At the heart of the Initiative is the belief that the community, guided by a consortium<sup>1</sup> of individuals and organizations from many sectors, can best design and implement the services needed by the women and children in that community.

This spirit of avoiding “business as usual” in government by encouraging community flexibility and ownership was codified in the Healthy Start guidance. The guidance specifies that each federal Healthy Start site must have a consortium and indicates the types of individuals and organizations that might belong to such a consortium. The consortium is so integral to the Initiative that the grant award partially depends upon it; 25 percent of the funding decision score was based on the level of collaboration demonstrated in the initial grant application.

---

1. Note on nomenclature: Many Healthy Start sites use different words to describe collaborative efforts at different levels. For the sake of simplicity, in this paper “consortium” describes the collaborative effort at the project level, and “local council” describes collaborative efforts in the smaller service or target area.

By emphasizing consortia, the Healthy Start Initiative focuses the power of collaboration on the problem of infant mortality. A well-organized community can have benefits that ultimately reduce maternal and infant mortality and morbidity rates. These benefits, described in *Healthy Mothers, Healthy Babies: The Community Connection—A Guide to Community Planning and Organizing*, include increasing the public's understanding of the problem, strengthening the public's commitment to deal realistically with the problem, using existing resources more efficiently and effectively, and mobilizing additional resources. In addition, women and children can have greater access to a continuum of care, as providers of services cooperate more fully and are more accountable for their programs.

The key reason that collaboration is essential to combat infant mortality is found in the complexity of the problem itself. Because infant mortality is affected by socioeconomic conditions such as poverty, inadequate housing, unemployment, racism, and violence, no single organization can solve the problem. For many pregnant women, personal issues such as substance abuse, youth, and a general feeling of hopelessness compound these difficulties. Only a collaborative effort within the community can create the long-term vision needed to attack the problem from a myriad of angles. This is not a simple task.

Creating thriving collaborative efforts requires a commitment to move beyond the cooperation and coordination found in many communities. Habana-Hafner and Reed describe the progression of these partnerships in *Partnerships for Community Development: Resources for Practitioners and Trainers*:

- Cooperation, or networking, is the most informal of these arrangements. Its goals are exchanging information, operating in a more rewarding way, exchanging nonmaterial resources, and learning about others.
- Coordination is somewhat more structured. Its goals are trying to avoid duplication of services, operating more efficiently, sharing some material resources, and exploring more meaningful connections with other organizations.
- Collaboration is the most sophisticated arrangement. It is defined as a process in which partners create common goals; share and create material resources; jointly plan, implement, and evaluate new services; and delegate individual responsibility for joint efforts. Partners use the power of their organization as they negotiate for comprehensive programs. In true collaboration, members must have the authority to commit staff, financial resources, and facilities, as well as the power to alter existing policies and procedures to advance common goals.

As Melville and Blank argue in *What It Takes: Structuring Interagency Partnerships to Connect Children and Families with Comprehensive Services*, "Real progress toward large scale comprehensive service delivery is possible only *when communities move beyond cooperation to genuinely collaborative ventures* at both the service delivery and system level" [italics added]. Healthy Start consortia that are truly collaborative can change not only the service delivery system, but also the community itself.

Melville and Blank explain that five critical factors shape the development of collaboratives: *climate*, *people*, *resources*, *processes*, and *policies*. The social and political *climate* can range from highly supportive, when the issue at hand is a top priority for many key decision makers, to nonsupportive, when the community is preoccupied with other concerns or negative relationships. The second variable concerns the leadership and participation of the *people* involved. The third component is the availability of *resources* to effect permanent change. The fourth variable is the creation of *processes* that establish a shared vision, build a team, and handle conflict constructively. The fifth element comprises the set of governing *policies* of each agency and the state and federal governments.

The effectiveness of the consortia in advising the Healthy Start projects and in mobilizing community involvement will be fundamental to the outcomes of the Initiative. Two years is a very short time in which to organize the community so that, at this point, the effectiveness of the consortia cannot be determined. This paper, instead, examines the challenges the Healthy Start projects have faced in developing consortia. Five consortia were chosen as a representative cross section: Baltimore, Chicago, New Orleans, Northwest Indiana, and Pee Dee, South Carolina. Information was gathered from as many participants as possible through site visits, consortia and committee meetings, and interviews with project directors, staff, consortium members and consumers.

These five Healthy Start projects exemplify how the five critical factors shape the development of collaboratives. In addition, several common challenges quickly emerged: *determining the structure of management and governance*, *increasing consumer involvement*, *handling race and class issues*, and *boosting economic development*. By examining the approaches used by the five projects to deal with these challenges, this paper presents an understanding of how consortia can develop effective strategies.





## **The Effects of the Five Critical Factors**

Healthy Start consortia are affected by factors common to all collaborative efforts: as stated earlier, climate, people, resources, processes, and policies. Some of these factors can be enhanced by the skill of the individuals involved. Good leaders can help to create facilitative processes, obtain the necessary resources and allocate them effectively, and change policies as necessary.

By definition, though, the climate is beyond the control of those involved in the collaboration. Sometimes, individuals involved in previous efforts have paved the way for success and created a supportive climate. Other times, forces outside the collaboration may create conditions that overwhelm or overrule its efforts.

---

### **How does the social and political climate affect the development of the Healthy Start consortia?**

**A community with some experience in collaborative efforts may be more receptive to the type of changes needed for Healthy Start.**

A successful collaborative experience in a community is likely to create a climate that fosters more collaborative efforts.

- In South Carolina, the former state health commissioner, Michael Jarrett, had been working for several years to create partnerships among agencies and organizations. He was skilled at bringing people together and leading them into collaboration. Prior to his death, Jarrett created an environment in which people became accustomed to working together, so that even when the project lost his leadership, the shared experience remained to nurture Healthy Start.
- After the 1988 infant mortality statistics were published, a group from the Northwest Indiana communities of Gary, East Chicago, Hammond, and Lake Station convened to look at the problem and develop strategies for reaching solutions. The infant mortality committee, whose membership was even broader than the present consortium, worked together to identify and fill gaps in services. The committee also launched Infant Mortality Awareness Week. This activity marked the first time that these cities had worked together on an issue such as infant mortality, but their collaborative successes enhanced their ability to create a functioning consortium for Healthy Start.

**Successful experiences in designing service interventions may not translate into successful collaborative efforts.**

A community that has created some successful interventions in service delivery does not necessarily have a climate conducive to collaboration. Sometimes, interventions that are successful in the short run bring with them the cost of alienating members of the community. Not only are these interventions less likely to be sustainable, but they may also create a climate hostile to collaboration.

Several Healthy Start projects were founded on other infant mortality reduction projects. The lessons learned from the former projects' interventions provided valuable information for the Healthy Start planning process. The actual projects, however, were like puzzle pieces which had to fit into a whole new framework. Sometimes the pieces fit well; the former projects facilitated the groundwork for the Healthy Start project. Some of those former projects were able to make the transition into Healthy Start projects by first focusing on building strong consortia rooted in the community; these consortia could then manage the project.

At other times, the puzzle pieces did not fit well; from its acquired reputation or history, the project impeded community involvement and enthusiasm for successful collaboration with all available resources. At some of these sites, the transition to the Healthy Start model might have consisted essentially of a name change

to Healthy Start, with the project team concentrating on creating interventions to add to its existing framework. In these cases, others in the community feel less ownership in Healthy Start; they may feel as if they are mere adjuncts to an ongoing endeavor. Other organizations may focus their attention on trying to get Healthy Start to fund their special-interest project, rather than focusing on what is best for the entire community. In these instances, Healthy Start seems more like a bank than an Initiative that launches collaboration and transforms a community.

**Local politics, or other forces outside the Initiative, can exert a negative impact on Healthy Start collaborative efforts.**

Like most programs, Healthy Start programs are vulnerable to forces in the larger world. Legislation at the state or national level can override the programs being implemented. Forces of nature, like hurricanes or floods, can wipe out communities and divert the energies directed to the program. More commonly, local elections will change the political landscape and change the body of decision makers in the community.

- The mayor of New Orleans is in his final term and the city's Department of Health is the grantee for Healthy Start. Since the project director for Healthy Start was appointed by the mayor, the relationship between the grantee and the consortium may possibly change under a new administration.

---

**What type of people are needed to lead  
Healthy Start consortia?**

Even in a climate conducive to building collaboration, the leadership within the consortium is critical. The project director, the chair of the consortium, and other leaders must have the skills to work together, share power appropriately, and listen to and empower others. They must also have either a history of credibility in the community, or they must have been distant enough from it to be seen as neutral outsiders. Most importantly, they must be able to articulate a vision, then let that vision be reshaped by the community until it becomes a shared vision, owned by all involved in the collaboration and nurtured through its fruition.

**Leaders must be credible and must have the trust of the community, (including both providers and consumers).**

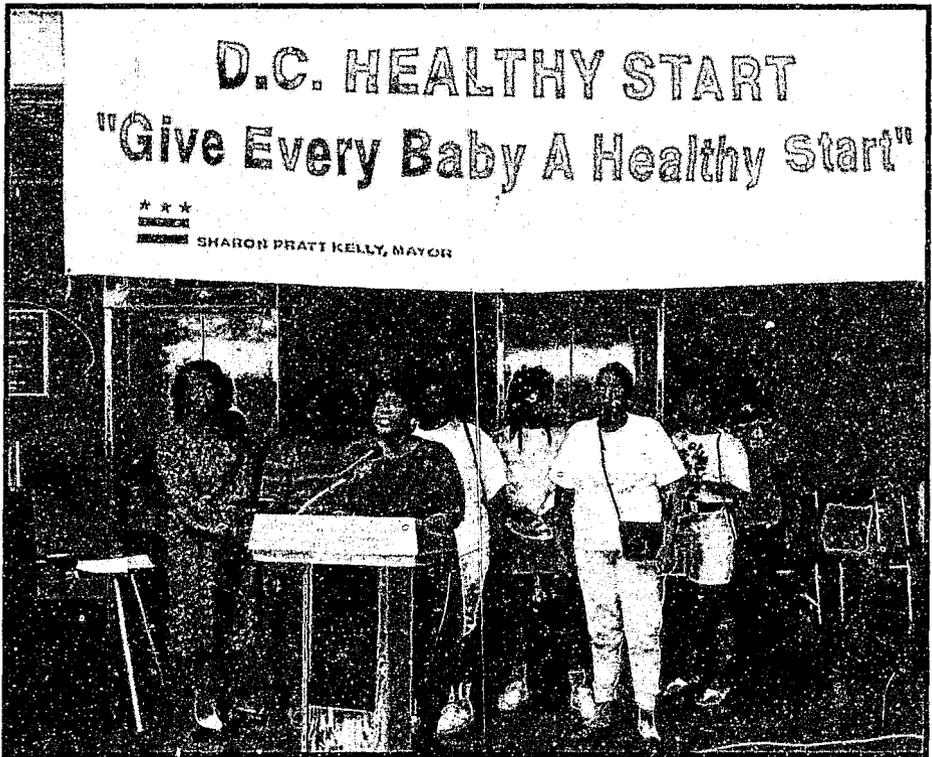
Both trust and credibility are extremely important. Providers and consumers may be wary of new Initiatives. Providers are not sure that the new program will be in their interest. What if it reduces their importance to the community, lures away clients, or hires away staff? Consumers may be afraid of being used as tokens when the Initiative wants to showcase them, while not being able to meet their own needs through the program. The most common reaction of both providers and consumers is cynicism. Will this program really be any different? What is the commitment to collaboration? As Habana-Hafner and Reed describe in *Partnerships for Community Development: Resources for Practitioners and Trainers*, "Trust has to do with overcoming people's resistance and fear while strengthening their belief that they can and should make a difference." Program leaders must be strong, articulate, and assertive to overcome the sources of cynicism facing the project.

- Some community leaders in New Orleans had seen other projects leave little impact in their neighborhoods and so were skeptical that Healthy Start would make a difference. As one community leader said, "Many community groups were resistant to joining. We researched the players. We wanted to make sure that we could trust the people doing the program. We wanted to make sure it was community people doing the program."

**Effective leaders for collaborative efforts know how to share power and nurture leadership in others.**

Good leaders recognize what others can do and give them the resources they need to be able to succeed. They understand that sharing power increases the chances for success in a consortium. If people are involved in decision making, they have a stake in the process and they will work very hard to ensure the program works well.

- One consortium member, in listing the many attributes of her leader, condensed these into one essential talent: "Everyone has skills, but she helps us use them."
- The Leadership Council for the New Orleans consortium has five members, each representing a different segment of the community. These five members share power by rotating the task of chairing the consortium, so the consortium does not feel that one interest group leads the others.



**The project director must be able to give power to the consortium.**

If Healthy Start programs are to have strong consortia, it is because project directors—staff members of the grantees—are able to empower the consortia. Successful project directors are able to work well with individuals who are not under their direct control.

- The project director for the Chicago site has many years' experience with grassroots organizing so she understands sharing power. She is able to function as an intermediary between the grantee, the state, and the consortium, explaining each side's perspective to the other.

**The chair of the consortium must be recognized as the leader of the local Healthy Start program.**

Consortia that choose their own chair are more likely to grant the chair the authority needed to manage the diverse group. This authority is vital as the chair tries to balance the voices of the traditional sources of power, such as big hospi-

*"I have seen the evolution of this program.  
It has evolved into a program with a vision,  
a vision that has caught on."*

tals, with the voices of consumers or small service providers. The chair of the consortium must know how to generate dialog on issues and encourage problem-solving discussions while keeping the group on track.

- To find the best person to lead its consortium, the Baltimore grantee polled consortium members for their opinions. The individual that was chosen is viewed as a solid leader in the community, neutral in turf battles, and committed to the issues.

### **The goal of the leader is to serve the community.**

Good leaders understand that the origin of the infant mortality problem lies within the community, and thus, in the end, it must be the community that addresses the problem. Leaders understand that their role is to facilitate that process and serve the community in its efforts.

- The project director for Healthy Start in New Orleans stated: "We are here to serve the community and we wanted to include the community as much as possible. We never felt that it was a Department of Health project, because the Department of Health could not solve the problem of infant mortality in and of itself."

### **Leaders must be able to articulate a vision and share it with others.**

Effective leaders recognize the importance of shared vision, for it is through this vision that members feel part of the team and create the energy that will carry them through the difficult periods.

- After two days of meetings, one consortium leader reflected with gratification, "I have heard many good ideas that have been internalized by the participants. We have articulated a vision that is shared by all."
- Another member concurred with this evaluation: "I have seen the evolution of this program. It has evolved into a program with a vision, a vision that has caught on."

**Individuals involved in collaboration must have the authority to make decisions.**

Consortium members who represent service providers or other resources must be given legal authority by their organization to make decisions regarding their organization's mode of participation. They must be able to commit their organizations to action when it is required.

- In Chicago, the local council of Henry Booth exemplifies how weak a council can be if its members have no authority in their agencies. Most of the key agencies in this area are involved, but the decision makers are not sitting at the table. Midlevel staff attend, assigned by their supervisors. The session is generally just to share information. There is little discussion on how to solve problems, and none of the agencies offer their resources to reach solutions.
- The members of the Executive Committee of the Northwest Indiana consortium have the authority to speak for their organizations. If the need for space or a change in program priorities comes up at a meeting, the committee discusses the issue because it can look to its membership for a solution.

---

### **What type of resources facilitate the work of the consortium?**

There is no question that a commitment of financial resources for a significant period of time (at a minimum, the five-year funding period of the federal Healthy Start Initiative) facilitates the work of the consortium. While the continued award of federal Healthy Start funds is predicated on effective and appropriate use of previous years' grant funds, consortia know that funding is reasonably predictable. A multiyear funding commitment gives the individuals working on the program time to bring their ideas to fruition. They have the freedom to devise longer-term innovative solutions, rather than being forced to create instant programs with results that could fizzle out tomorrow. Many Healthy Start participants feel that even five years is too short a time frame to create the kind of changes needed.

A significant commitment of outside financial resources, however, is not absolutely essential for a successful consortium. Strong leadership, a positive cli-

mate, and other factors can compensate for the lack of financial resources to a surprising degree. The Milwaukee Healthy Start program, for example, has not been part of the federally funded Initiative, but it has been able to create a consortium and achieve remarkable results with its small budget.

No matter what the level of outside funding, perhaps the key is the ability to help the community use all of its resources in a different way. One consortium member noted, "No community is really resource poor; it is just how they choose to use those resources. What would it take to get the people in the environment to foster solutions?"

### **Special resources devoted to community organizing will make a difference.**

- New Orleans has established a community development team, with the primary mission of organizing the community. Led by a consultant with many contacts and extensive experience in the health community, the team includes community development associates who work in each service area trying to organize the community and launch the local councils. The community development associates identify and contact various resources in the neighborhoods and have personal meetings with key leaders. They share the Healthy Start mission with service providers, discussing barriers to access and working with them to improve services. They also recruit service providers, along with consumers and community leaders, for the local council. A bilingual consultant is also part of the team, as is the economic development consultant. The team has facilitated community involvement in Healthy Start in all phases of the project, from sponsoring town meetings to bringing community leaders into the process of developing the comprehensive plan.

### **Resources for leadership training can also be important.**

Successful collaborative efforts depend largely on the skills of community leaders, and these skills can be nurtured. Training can help community members hone their leadership and management skills so they learn how to devise their own solutions to the community problems. Training can be particularly helpful to consumers, to give them the confidence to assert their ideas in forums with professionals.

- As Chicago's comprehensive plan states, "Since many consumers feel ill-at-ease interacting with professionals and officials, Healthy Start funds

*"The tone set from the beginning was that every opinion was valued and respected," noted a New Orleans consortium member. "Everyone at the table was equal."*

have also been set aside to provide consumers with social skills and assertiveness training."

- New Orleans has designed a leadership training course for consumers and others on the leadership councils. Planned for spring 1994, this leadership training course will attempt to develop communication and negotiation skills as well as to teach participants about systematic influences such as politics, racism, and the media.

---

### **What type of processes facilitate the work of the consortium?**

Members in the consortium have to be willing to participate; to provide information, ideas, and resources; and to handle criticism constructively. The processes that facilitate this type of cooperation enable the consortium to be productive and to keep members active in the work.

#### **Consortium members must be able to work as a team.**

Consortia are more productive if the members feel that they are part of the team, that they are important to the process, and that their opinions are listened to and considered.

- The Chicago consortium conducts its meetings according to parliamentary style, with strict attention to *Robert's Rules of Order*. Though the debate on the issues is quite outspoken, it is also channeled by the formal rules, which appear almost stiff. As the members of the consortium use the rules, it is apparent that they all have agreed to the process, because they feel part of it and empowered by it. They know that they will be given an opportunity to voice their opinion at the appropriate time and that others

will listen, and they know that the discussion will stay focused and not be distracted by someone rambling on about an irrelevant point.

- "The tone set from the beginning was that every opinion was valued and respected," noted a New Orleans consortium member. "Everyone at the table was equal."

**The consortium must be able to handle conflict and solve problems constructively.**

One common type of conflict occurs over the allocation of resources. In most consortia, at least one group does not receive the resources that it feels it deserves. When the consortium makes the decision on how to allocate resources, the decision has more legitimacy in the community.

- A service provider in one of the consortia assumed that resources would be allocated to him. This individual was focusing not on the needs of the community but on his own gain. The rest of the consortium felt the provider was disruptive to the group process and he was asked quietly to behave or to stop coming to meetings.
- A group of lay midwives in New Orleans believed that their services should be an important part of expanding access to care. The perception in the community, however, was that home births with midwives would be considered second-class care by women in the community. Historically, low-income pregnant women have experienced such frustration and difficulty in accessing medical services that only first-class attention by the hospitals would convince them that the medical system finally valued them. Community activists presented their case to the lay midwives and to the rest of the consortium, so that all realized that the decision not to allocate significant funding to the midwives was a decision of the consortium and not a matter of the grantee playing favorites.

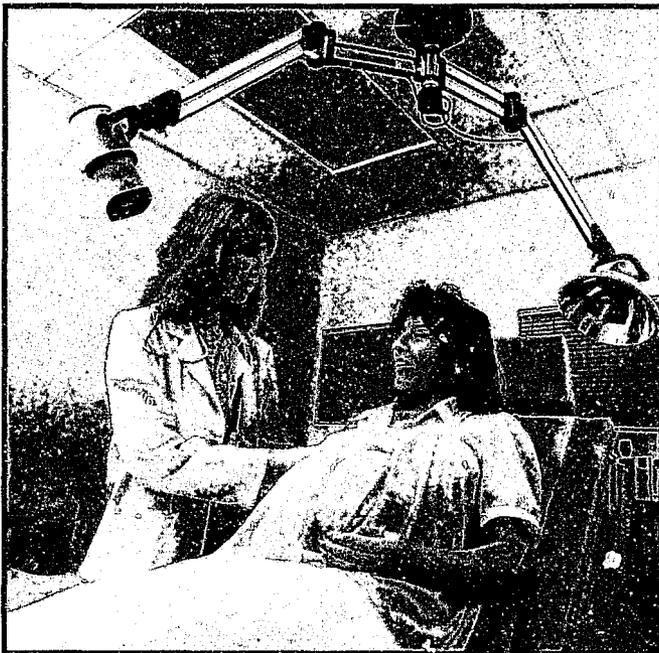
A second common type of conflict is conflict of interest. This can be a problem when those who are active in the consortium, making funding or program decisions, want contracts from the consortium. This tension occurs frequently because many Healthy Start communities are served by a small number of providers.

- Members of the Chicago consortium are concerned about this type of conflict of interest and are delineating conditions for avoiding it in their "rules of governing."

**Consortium members must hold each other accountable for their actions.**

Including many groups in a collaborative process, one of the major advantages of a consortium, becomes a disadvantage if members are permitted to back out of their commitments. Some consortia leaders may deal with problems by trying to exercise unilateral authority, but this can destroy the spirit of collaboration. Effective leaders instead create an environment in which consortium members hold each other accountable.

- As one New Orleans consortium member suggested, "Our biggest success was getting people into the dialog and making them feel accountable to the community. The process made the service providers feel accountable for the care they were giving."
- Can the consortium deal with a member who breaks the rules of the collaboration? In Chicago, the city greatly reduced its proposed allocation of funds to several agencies that were also partners in the consortium. Because the city acted unilaterally, creating this proposed budget without any consultation with the consortium at the same time that city staff were sitting in on the meetings, consortium members were very angry and felt that the city had not acted in good faith. They demanded that the city be called to account for its actions and requested that the partners reexamine their commitment to the process. Although the proposed budget would



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directly affect only three agencies, consortium members called for collective action. They developed strategies on how to best use the talents of the partners to bring pressure to bear on the city.

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### **What policies do the grantees and the consortium members bring to the table that facilitate or impede collaboration?**

**The grantee is the focal point for collaborative efforts.**

Generally, grantees are not structured to facilitate collaboration. These agencies can have resources that benefit the project, such as a press office or a financial accounting system, and they can call on staff with experience in designing service interventions. But most grantees are state or city health departments, with their own bureaucratic processes that must be followed. In addition, many agencies involved in the consortium have their own bureaucracies. When several bureaucracies try to work together, common barriers include different personnel systems, fiscal accounting, subcontract management, eligibility requirements, rules of confidentiality, or client identification numbers.

Various Healthy Start sites have handled these policy barriers differently. Most grantees struggle with redefining policies at their organizations so that they can work better with other organizations. Some sites have instead used or created a "neutral" agency as a grantee, one that will have fewer bureaucratic policies that need changing.

- In South Carolina, former state health commissioner Michael Jarrett and the governor had the vision to give the lead to United Way rather than to a state agency. They felt that state agencies were still too likely to continue doing "business as usual," including battling over turf. A neutral agency such as United Way could mediate more effectively. State agencies were partners with United Way in creating the project and helped to hire appropriate staff.
- The Northwest Indiana Health Department Cooperative was created in the planning process for Healthy Start. It has been a collaborative from its inception, combining resources and staff from four cities. As a new entity, it could be seen as neutral, with no history to overcome.



## **Challenges in Consortium Development**

The process of organizing the community and developing a consortium brings inherent challenges. Issues of management and governance tend to dominate in the beginning, as communities try to create structures that fit their particular situation. The design of Healthy Start, with its mandated goal, its division of responsibilities, and its broad scope requiring several levels of collaboration, makes management and governance particularly tricky.

Three other challenges are common to community organizing. The Healthy Start programs, like most communities trying to use collaboration to improve service systems, are unsure how to increase the role of consumers in the consortia. Race and class divisions can creep into the process and undermine organizing efforts. The need to improve economic development is also critical.

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### **A. Management and Governance**

From the beginning, the individuals who designed the federal Healthy Start Initiative created special challenges for the local programs as they attempt to create a suitable framework for management and governance. Three types of issues dominate: how to handle a time-consuming process in a short time frame, how to divide responsibility, and how to structure a myriad of complex collaborative relationships.

## **1. Short time frame**

First, those trying to implement Healthy Start face an inherent tension between the mandated goal and the mandated process. On one hand, the Healthy Start Initiative specifies a very ambitious goal—to reduce infant mortality in the project areas by 50 percent in five years. On the other hand, the Initiative also requires community involvement in the form of the consortia.

It takes time to truly involve the community in the project. People have to be brought together to learn about the problem, focus on it, and search for the most appropriate means in their community to change it. This time-consuming process, prescribed in the design of Healthy Start, clashes with the ambitious goal of the Initiative that requires a big change in a short time. There can be inherent tension between the grantee's need to reach the goal of reducing infant mortality by 50 percent and the consortium's need to examine what is best for the community.

Some grantees feel that the only way to reach such an ambitious target in such a short time is to organize a blitzkrieg of interventions, ensuring that the women and the children in the project area have all the services they could possibly need. These interventions may be extremely well designed and may meet the pressing needs of many individuals, but the community might not feel ownership for the program. The community is kept informed but does not have any real control over decisions.

Other grantees are excited about the opportunity to organize their communities around this issue. They believe that it is more important to mobilize their communities, help providers work together, and change the system even if the effort takes longer and thus slows implementation of new service delivery. Many feel that the 50 percent target was unrealistic anyway, so to forgo community development is to miss the real opportunity of Healthy Start.

## **2. Division of responsibility**

A second issue in management and governance comes from the division of responsibility. Healthy Start was designed to foster community involvement in the form of the consortium which, philosophically, has the responsibility for advising the grantee on the best way to use project funds in implementing its programs and activities.

Based on a competitive review of Healthy Start comprehensive plans devised by consortia from around the country, Healthy Start grants were awarded to spe-

cific organizations, usually city or state health departments. In most cases, these organizations are agencies that existed before Healthy Start and have a mandate, staff, and many programs encompassing other areas. These organizations, because they were awarded the grants, have the fiscal responsibility to ensure that the funds are used appropriately. The advantage of having a specific grantee overcomes a common weakness of community-driven programs, for it ensures that full-time grantee staff can fill essential roles, from clerical support and meeting planning to interagency coordination and program monitoring. Given their ultimate legal accountability, however, some grantees are more comfortable than others in conveying more decision-making responsibilities to the consortium.

**When the consortium is active in managing the project, the line dividing the grantee's responsibilities from those of the consortium is constantly being examined.**

Since the grantee agency has fiscal responsibility, it can request periodic reports from those organizations receiving funding. Most grantees have established this reporting system for the project. In one case, however, the consortium also requested monthly fiscal reports from provider agencies so that it could monitor expenses, and, if necessary, give guidance to the organizations on how to use their funds.

**Community involvement is time consuming and will slow the creation or expansion of service delivery interventions.**

It is 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.

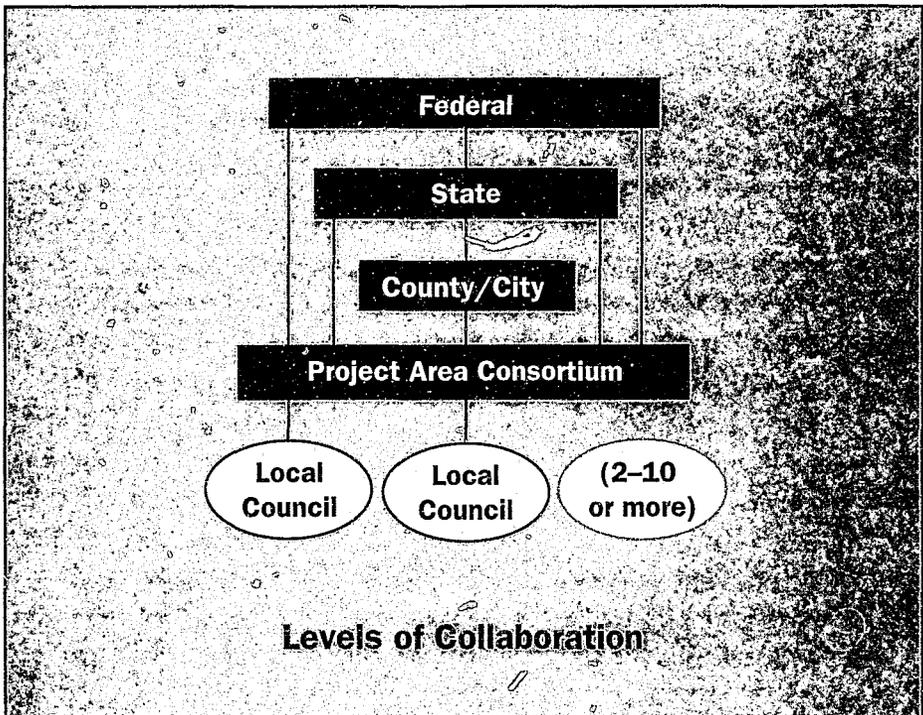
- As a staff member of one grantee agency said, "It would be so much easier to write the [guidance and manuals] ourselves. We cannot even draft materials for these committees to work against. Everything has to be written by the committee. So we spend all of our time in meetings!"
- The Chicago consortium is very involved in the management of Healthy Start. Consortium members, in their work on committees, write the requests for proposals and review the proposals received. They have written all project materials, including the guidance for the development of the family life centers and the manuals for case management.

- In the Pee Dee region, the local councils review the proposals and make recommendations on allocation of resources. The consortium reviews these recommendations and approves the budget.

Even when consortia are so involved in the management of the project and essentially have philosophical responsibility for it, the fiscal responsibility legally must remain with the grantee.

### 3. Levels of collaboration

A third challenge for governing Healthy Start derives from its size and complexity. With project areas consisting of either several rural counties or large portions of major urban centers, integration of services across the project area is a major concern. At the same time, service delivery issues (including questions concerning what, how, and to whom services are delivered) are supposed to be determined at the local neighborhood level. The guidance for Healthy Start discusses these dual needs and encourages collaboration at and between all levels,



thus multiplying the complexity. Since collaborative efforts are also needed at state, regional, and federal levels to support local endeavors, the result can be a maze of relationships.

*a. Project area consortium*

Creating a project area consortium has been a top priority for all sites. Some derived the structure and mandate of this consortium from the Healthy Start guidance, while others adapted the concept to conditions in their community. In many cases the project consortium grew out of the group that submitted the initial grant application, and was very involved in developing the comprehensive plan.

The typical consortium is composed of service providers, community organizations, politicians, and several representatives from the local councils. Most consortia also have business and church representatives, though these individuals are often harder to recruit. Community members and consumers are the most difficult to recruit, so their "slots" on the consortium may be waiting to be filled.

- Baltimore, Chicago, and New Orleans all have only slight variations of this typical structure, with a project area consortium and several local councils. Collaborative efforts at the state level are more informal.
- The Northwest Indiana Health Department Cooperative is a collaborative agreement among the four health departments covering the project area. The consortium is unique because its 100 members include 20 members from each of the four local councils and 20 members who represent agencies that serve the entire project area.
- The Pee Dee Healthy Start program is based on a triad of collaborative efforts. Local councils in each of the six counties determine how best to create or expand interventions. A regional council, consisting of leadership from the local councils, focuses on regional consistency and sets priorities. The project consortium, located at the state level, governs overall program issues.

**As consortia evolve, they have struggled with the issue of open or closed membership.**

Project consortia try to balance the need to be open to the community and include everyone who wants to join, and the need to have a group small enough to be productive. Resolution of the conflict usually involves creating and adapting

some form of a three-tiered structure: (1) the consortium, which has a more open membership; (2) working committees, which analyze and make recommendations on a specific subset of the consortium's work; and (3) the small executive committee, which is the leadership body and often the locus for problem solving and decision making.

- Baltimore initially tried to ensure that only those who were critical to Healthy Start activities were members of the consortium and to limit membership to 60. When that was not politically feasible, the consortium opened up and became more of an information-sharing body. A smaller, 19-member executive committee was formed, with the consortium members choosing representation.
- The Chicago consortium permits anyone to attend meetings. The voting members of the consortium, however, are representatives from the working committees and are chosen by those committees.
- The New Orleans consortium grew to more than 300 individuals during the planning process. Since that time, the group has experienced a natural attrition, but consortium members wanted to make sure that those involved were committed to the process, so they created a "consortium pledge" for members to affirm their commitment.

#### *b. Local councils*

Since most Healthy Start consortia have created or expanded community service delivery, the local community should be firmly invested in determining those interventions. Most Healthy Start consortia have created local councils to oversee the operations in the target or service area. Much of the first two years, however, has been devoted to helping the consortia to function better, so forming local councils has been a secondary priority. Of the five sites studied, Northwest Indiana is an exception, since its consortium consists of the local councils.

Most of the other consortia have a set of local councils that are in different stages of development, depending on the experience in the community. Some local areas have boundaries that are not based on existing service delivery systems, school districts, zip codes, or other traditional ways of determining neighborhoods. These service areas seem more contrived, a bureaucratic invention formed because of the statistical requirements of the grant, rather than because residents feel they are part of one neighborhood or community.



These “contrived” local service areas may take more work to organize, though progress can be made.

- The Tulane/Gravier service area of New Orleans comprises many subcommunities—Latino, African American, and white. Located in part of the business district with several major medical facilities, the service area traditionally has not thought of itself as a community. It was the only service area of the New Orleans project that did not have a town hall meeting during development of the comprehensive plan. The Healthy Start community development team has targeted extra resources to organize this area, including a consultant to work with the Latino community, and the community is planning a bilingual town meeting.
- It is common belief that the South Carolina communities of Darlington and Hartsville have been competitive for a long time. Healthy Start has brought together diverse organizations and groups from all communities to work toward the goal of reducing infant mortality. The capable leadership from Pee Dee Healthy Start has helped the communities view the influx of resources as a rare opportunity and a valuable incentive for forging new ties.

**Some of the weaker local communities need concentrated efforts in community organizing.**

Some of the local councils are meeting together and discussing issues. Skilled leadership may be difficult to identify, however, because members are frequently not familiar with one another. Members are in the process of learning about each other and learning to trust each other, and they do not yet form the cohesive teams needed to manage the local interventions. With outside training, the councils could progress even faster. Efforts to create cohesive teams and develop leadership skills could yield desired outcomes for Healthy Start and long-term benefits for the communities. Recognizing these benefits, some of the Healthy Start sites have arranged for training and technical assistance in community organizing.

**Other local communities were already organized and have strong community leadership.**

- In Chicago, the Humboldt Infant Mortality Reduction Initiative was involved in community organizing before Healthy Start. The Humboldt initiative serves its community in many ways, from lead screening and immunizations to health education and case management. Community leadership training is a critical component of this effort. The trainer exposes all the clients to community leadership, the functioning of a consortium, parliamentary procedures, and other ways to be part of the larger power structure in the community. The goal of the Humboldt initiative is to reduce infant mortality by involving everyone in the community in some way, whether through church, Little League, politics, or other activities.
- In New Orleans, the preexisting St. Thomas coalition includes all service providers and active leaders in the community. The coalition decides what is best for the community and will work only with funders who understand that the coalition, not the funder, is in charge. The coalition does not accept donors who want to dictate terms to the community.

**Communities that are organized are more likely to challenge Healthy Start.**

- While the Humboldt Infant Mortality Reduction Initiative in Chicago has more than 200 linkage agreements that delineate its extensive collaborative arrangements with other organizations, the Humboldt initiative believes that all government entities will be "the enemy" at one time or other, because government does not always place the interests of the com-

munity first. On one issue, the Humboldt initiative will be a partner; on another, it may be the challenger. While this philosophy means that other organizations, like the Healthy Start grantee, cannot always count on the Humboldt Infant Mortality Reduction initiative to support their side, they also know that the Humboldt initiative places the needs of the community first and will fulfill its agreements. The organization has integrity and ensures that the community's voice is always heard.

- The power of the St. Thomas coalition in New Orleans also presents a challenge. The coalition did not want a separate local council for Healthy Start in the community; instead the Healthy Start council had to be constituted from the coalition. While this structure means that the local council may be a contentious partner in the New Orleans consortium, it ensures that the work will be rooted in the community.

### *c. Collaborative efforts at the state level*

For collaboration to be effective, the Initiative usually needs support from the state as well. State programs and policies can support or undermine local efforts. Since part of the Healthy Start grant application required indication of support from the states, the states generally do not negate the work at the local level by issuing contrary mandates. Some states, however, are more active than others in the collaborative efforts of the Healthy Start projects.

- In 1991, Governor Carroll Campbell of South Carolina spurred interest in participating in Healthy Start, and assigned the appropriate staff at the state level to create the application. Governor Campbell has stated that reduction of infant mortality is one of his priorities. This high-level support ensures that all relevant provider agencies are actively involved in the Initiative. The Pee Dee consortium meets in the state capital, rather than in one of the target counties, so that all state agencies that provide services to women and children can play an active part.
- The Illinois Department of Health is the grantee for Chicago Healthy Start, so the state is very active in the project. Moreover, Chicago consortium members facilitate cooperation at the state level by sitting on committees that affect the work of Healthy Start. Project Cornerstone, for example, is trying to define the health data set needed by the state. Consortium members participate in that project to coordinate plans to gather the Healthy Start data with Project Cornerstone. Members also sit on the quality



assurance subcommittee of the medical advisory committee and the committee for Medicaid case management.

*d. Collaborative efforts at the federal level*

At the first grantees meeting, the Healthy Start grantees asked the Healthy Start central office staff to ensure that the collaborative efforts expected at the local level would be replicated at the federal level. The grantees stressed that federal agencies should listen to the localities to learn of their needs, and then should work together across agencies to meet those needs.

The central office staff has had some successes as well as some hardships in meeting this request. Almost all requests from the local level for specific help have been answered. The Department of Labor granted waivers so that Healthy Start staff participating in Jobs Training Partnership Act programs retained their eligibility for benefits. The Special Supplemental Food Program for Women, Infants and Children (WIC) has increased slots for clients and hired additional nutritionists.

Most often, if federal agency staff members with authority are sitting at the table, they are very willing to collaborate. Healthy Start has quarterly meetings with WIC to discuss collaboration, including outstationing efforts and ways to increase the cultural sensitivity of some of its workers.

On the other hand, federal agency efforts to be proactive and to create a match between federal resources and programs and the needs at the local level have been

more limited. This difficulty is due to a variety of reasons, including delays caused during the transition between presidential administrations and the problems encountered by federal agencies working across different funding entities.

Central office staff have sent to the Healthy Start grantees all requests for proposals (RFPs) that are applicable to the local programs. However, most local programs are so busy trying to make their services operational that applying for additional federal funding has not been a top priority.

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## **B. Consumer Role**

Healthy Start consortia also face the challenge of integrating the voice of consumers into the decision-making process in a meaningful way. The guidance states, "Most importantly, residents of the community, the ones with the greatest personal stake in the success of Healthy Start, must be involved in the planning, decision making and solutions that come out of the Healthy Start effort." While all of the Healthy Start sites would agree that consumer involvement is necessary, most struggle with the best way to obtain consumer participation in a consistent and sustaining manner. It has been particularly difficult to include adolescents in the process.

### **What is a "consumer"?**

The very word "consumer" is a charged word, like most words that try to describe this group of people. Most people would prefer a positive word that means "people who are partners with us as we try to provide and improve services they need," but most words have gained negative connotations through the years. For some, consumer connotes someone who deserves good service, and knows how to get it, as an "informed consumer" would shop for an appliance. Others focus on the consumer as one who uses; they might prefer the term "client," as in those who hire someone to give them professional services. Still others see "client" as a word that has been used too much in social services, connoting "poor people who do not have to be treated well." No word is neutral enough to signal the change in relationship that Healthy Start is trying to create. Only experience, not a change in words, will convey the significance.

## **How do the consortia define "consumer"?**

The Northwest Indiana consortium defines two types of consumers—general consumers (anyone who is not a provider or grantee staff member) and target consumers. Most consortia have a narrower definition, one that focuses on those who may use Healthy Start services. The most common type of consumer would be pregnant or postpartum women and their infants. The Healthy Start Initiative is broader, though, so all women of childbearing age (including adolescents) and their children are encompassed as potential consumers. Men might also be consumers because they are fathers or potential fathers. With such a broad Initiative, all community residents become potential consumers.

Some consortia take another approach, differentiating between those who are involved in the community and those who need help. Community activists are those who know how to fight for what is needed, and "consumers" are those who need help in accessing services and power to change their lives.

Differentiating between consumers and others is even more complicated because many Healthy Start providers have hired community members as staff. In those cases, the difference between "staff" and "consumer" may be only a Healthy Start paycheck, because the experiences of the women may be the same. These staff members can provide valuable feedback concerning what works in the community. Once they are part of the provider system, however, they cannot impartially monitor the progress of Healthy Start in the community.

- Baltimore Healthy Start found that, in hiring former consumers, many of its staff members were very empathetic to the situations of the women they were trying to serve. Some supervisors, however, found little difference in supervising these staff and working with their clients.

**Like most community organizing efforts, Healthy Start consortia have had difficulty in obtaining active, meaningful participation by consumers.**

Consortia can enable consumers to participate in Healthy Start in several ways. Opinion or feedback at one particular juncture is the easiest to obtain. All consortia have sponsored open forums where people can voice their opinions. Most consortia also have had focus groups, small private meetings that are convened to elicit consumer opinions on specific subjects.

Obtaining consumer opinion on a regular basis, so that the feedback is helpful in monitoring and managing activities, is more difficult. Generally, consortia have slots that are allocated to consumers, with mixed results. As one project director

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will convey the significance.*

asked, "How can we involve consumers without resorting to tokenism?" Having two people attend meetings but not speak is of dubious value. Some consortia try to overcome the problem of tokenism by having a significant portion of consortium membership allocated to consumers. Philadelphia, for example, has allocated 30 percent.

Other consortia have formed a special group for consumers, so they will share their opinions with each other, make recommendations for changes, and bring those recommendations to the decision-making body. With a separate group for consumers, they are more likely to be frank and open in their opinions, but having their feedback filtered through a screen in the form of recommendations might give it less impact.

- The Pee Dee counties' local councils have consumer advisory groups that discuss services in the community and make recommendations for change to the local council. Members of the Darlington County consumer advisory group are very outspoken in the meetings; as the chair quipped, "No one wears a hat in there." When the recommendations are made to the local council, however, all of the flavor and feeling are reduced to: "Providers must have cultural sensitivity." The providers sitting in the local council meeting could brush off the recommendation when read as part of a report, but they would have been forced to react to a room full of angry consumers.

Consumers usually have plenty to say but may not say it when part of a consortium with the power players in the community. One way to help them overcome this reluctance is to provide consumers with training.

- The Humboldt Infant Mortality Reduction Initiative, one of the local case management agencies in Chicago, has a community leadership trainer who mobilizes consumers and motivates them to come to the consor-

tium. The trainer teaches consumers about leadership, the way the consortium works, and *Robert's Rules of Order*. As the Humboldt Initiative representative to the consortium noted, "Everyone wants consumer input, but they will not be wished into existence. They need training and so we give it to them."

**Consumers may need special services to encourage their participation. The value of their time should not be underestimated.**

Most providers can attend consortium or local council meetings on paid time, as part of their job. In contrast, consumers come as volunteers, giving advice on their own time, and often using scarce resources to do so.

- The Chicago consortium provides child care and meals at their meetings. One of the local councils brings its consumers as a group to the meetings.
- The Northwest Indiana consortium provides transportation to the meetings, community forums, and Healthy Start services. In particular, pregnant adolescents from a home in Gary, Indiana, may be transported to services and consortium meetings.

In any case, whenever consumers are involved, the consortium has to ask itself a difficult question about the purpose of consumer participation: Is consumer opinion desired to improve the program or to change the consumers' and the community's view of themselves?

**It is critical to include adolescents as active participants in the consortium.**

One group of consumers—adolescents—have their own set of issues and may be particularly difficult to include in the project. It is imperative to do so, however, because adolescent pregnancy is usually a significant component of the problem and members of the community may be concerned about promoting or glamorizing adolescent pregnancy.

- Some of the teachers in the Northwest Indiana project area were worried that a special class for adolescent mothers would promote pregnancy, because other girls would want the same level of attention as that given to these young mothers.
- In New Orleans, a television advertisement created by Partners for Healthy Babies appeared to some viewers to send the message that pregnant ado-

*"We realized that the only way to ensure that we were operating from the viewpoint of the community was if the community taught us their viewpoint. They taught us who they see they are."*

lescents "would have all their problems taken care of" if they only joined the program.

If adolescents are involved in deciding which messages and programs are most compelling, they will also be more influential in dampening community concerns about the appropriateness of the messages.

**Creating adolescent participation usually requires policies and programs specifically geared toward meeting their needs.**

- In Northwest Indiana, the high number of pregnant adolescents has broadened the priorities of Healthy Start. Among the ideas being discussed by the consortium is the possibility of having a speaker's bureau of teenage mothers who would talk with other adolescents. Billboards and other promotional pieces may feature some of the teenagers involved in the program. Some pregnant adolescents are involved directly in the consortium, since a bus from the home for teenage mothers brings them to meetings. Some adolescents have already made a book about their impressions of motherhood, and the consortium is planning to build on this idea. A teen advisory group might be pulled together to work on a tangible project like the book and would then have both the team skills and the familiarity with the program to be a source for advice and direction on the program.
- South Carolina is also using activities in vogue with adolescents to bring them into Healthy Start. The teen life centers have had hundreds of adolescents involved in cheerleading, football camp, and a fashion show. With adolescents planning and leading the activities, they are already comfortable with the program and can be more active members of the teen life center advisory councils.

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## C. Race and Class

A third type of challenge comes from the tensions in the community resulting from racial and class differences. Often, this tension manifests itself when consumers feel alienated from the service providers who are supposed to serve them. In response to these feelings, consumers avoid seeking needed services.

These tensions can be the curve ball in the collaborative process. Some communities have been able to work through these tensions, and members have come to a new understanding of one another. In other communities, the tension splits the consortium so that effective community organizing becomes formidable. Sometimes race and class tensions divide the community from the grantee, so that the grantee cannot lead effectively.

**Differences between race and class exacerbate the divisions between provider and consumer and may be a significant reason for women failing to seek prenatal care.**

Almost by definition, providers of prenatal care are members of a different socioeconomic class (and often members of a different race) from the low-income pregnant women who need care. These divisions can create misunderstandings and even animosity. If providers and consumers are placed in situations where they speak and listen honestly to one another, these feelings and misunderstandings come to the surface. Sometimes, this honest discussion is enough to create better communication and working relationships between the two groups.

- The most common complaint of consumers is that they want to be treated with dignity. If providers did not treat them so poorly, these consumers might seek prenatal care.
- Before an infant mortality review process began, doctors at a Chicago hospital who could not find a biomedical reason for an infant death classified it as "client caused." As part of the infant mortality review process, workers visit the infant's home, observe the living conditions, and interview the parents. Doctors are often shocked at the reports and no longer feel that the parents are at fault in the deaths of these babies.



Racial and class tensions also surface between the community and the grantee or within the community itself. An exceptional amount of effort, skill, and sensitivity is required to handle these tensions in a way that heals, rather than exacerbates, divisiveness.

When the staff of a grantee agency are of one racial/ethnic/class group, and the target population is of another, the ensuing issues can create real difficulties. While some members of the community might be willing to seize the opportunity offered by Healthy Start and work with the grantee, others in the community might feel that the grantee lacks experience and skills in dealing with culturally sensitive areas, and thus lacks credibility in being sensitive to the issues of the community. Ethnic and class divisions and the lack of credibility and trust can have a significant impact on the progress of the grantee.

- One community insisted that the grantee hire a new project director who would be more sensitive to the residents' heritage. The grantee complied, and the new project director has been able to work well with the community.
- The leadership of Pee Dee Healthy Start at all levels—grantee, consortium, and local council—includes African Americans, Native Americans, and whites so that the leadership can respond to different segments of the community and work well with all of them.

- New Orleans Healthy Start has also tried to overcome class differences with a training program called Communiversity that is provided to all program staff as well as outreach workers. The Communiversity curriculum explores African American culture and history and has been a significant factor in improving communication and creating trust within the community and with the Healthy Start staff. As one staff member said, "We realized that the only way to ensure that we were operating from the viewpoint of the community was if the community taught us their viewpoint. They taught us who they see they are."

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## **D. Economic Development**

Most Healthy Start consortia have identified a fourth type of challenge: the need to create more economic development in their communities. If the Healthy Start consortia can facilitate economic development, they can improve the living conditions of the community residents, while at the same time increasing the visibility of Healthy Start in the community and creating a concrete legacy.

Most Healthy Start consortia discuss the importance of economic development for their community, but handle the issue very differently. This issue is generally not a high priority, in part because those in charge tend to have little experience in economic development, and in part because funds were not allocated directly to this component.

Economic development is defined in many ways. Several consortia believe that the ability of Healthy Start to spark economic development is generally limited to its ability to provide jobs for neighborhood residents. Providing jobs can be very important to the individuals receiving them and to the community; Healthy Start is the biggest employer in one of the Baltimore communities where it provides services. Healthy Start's impact as a jobs program will be very limited, however, especially given the five-year time frame.

For other consortia, economic development means involving the business sector in the consortium, so that business can provide goods and services to the program. Some consortia are trying to help businesses reduce infant mortality within their companies through programs to improve the health of their employees. Other consortia are focusing on economic development as an effort to create or expand entrepreneurial and job opportunities within their communities.

**A coordinator who specifically focuses on economic development can greatly increase the impact of Healthy Start.**

A special coordinator can focus the efforts of the consortium on economic development. Two of the project consortia that have hired these coordinators have not used routine Healthy Start staff procedures. In each of these examples, the appropriate person was identified because of his contacts and experience in the community, and special arrangements were then made so that this coordinator could focus on economic development in the Healthy Start areas.

- The economic development professional in the Pee Dee region of South Carolina works in the Healthy Start office specifically to coordinate economic development efforts in the region. A former General Electric plant manager who has also owned and operated a welding plant in the community, he is considered an employee of the South Carolina Department of Commerce. His salary, however, comes from Healthy Start funds and he is an active member of the Healthy Start team. With his experience and contacts, he has been an integral part of a team that convinced Tupperware to expand its plant from 700 to 1,300 employees in one of the target counties. He is now concentrating on creating indirect jobs (suppliers to Tupperware) in the region.
- The consultant for economic development for Healthy Start in New Orleans brings insights and skills to mobilizing the community around this issue. He has decades of practice in organizing, as well as managerial experience in agencies (such as serving as director of the Housing Authority). In addition to staffing the economic development committee of the consortium, the consultant attends meetings of the local councils to help stimulate their interest in economic development. He also works with members of the economic development committee to help groups with potential businesses to develop business plans and other materials needed to secure capital loans.

**An economic development committee of the consortium can help bring together the resources of the community to focus on this issue.**

If some consortium members devote their energies primarily to economic development, they will ensure that this issue remains a priority for Healthy Start.

- In New Orleans, economic development was the focus of one of the 11 subgroups that formulated the comprehensive plan. This focus group examined two types of issues. First, the group discussed how to access

resources to supplement the work of Healthy Start, both during and after federal funding. Second, the group outlined a plan to improve opportunities for the residents of the communities, identifying specific goals, objectives, and strategies.

### **Business representation on the consortium can be very helpful.**

Business leaders can raise awareness of infant mortality in the wider community. Some in the business community do not want to address the issue and are angry that "they are paying for poor people" in the present system of health care. Other business leaders understand that it is in their interest to address the problem and they can help to give credibility to infant mortality reduction efforts. These leaders can also use strategies to reduce infant mortality in their own businesses.

- The economic development professional in Pee Dee will be working through the Employers Association, a progressive group of chief executive officers and human resource managers, to highlight the issue of infant mortality. He is also trying to work with some businesses to develop strategies to integrate Healthy Start activities at employment sites.

Most consortia have been able to persuade businesses to donate goods and services to their efforts.

- In Baltimore, small local stores are cooperating in the incentive plan that allows Healthy Start consumers to earn products by fulfilling obligations.
- The Healthy Start celebrations in the Pee Dee counties received many donations of goods and services, including publicity, balloons, costume characters, food, and beverages.

### **Improving education can be a significant part of economic development.**

Many members of the Healthy Start communities lack the skills needed for successful employment. Improving the overall educational level in these communities could increase employment opportunities and thus economic development.

- The economic development committee for the Chicago consortium has an education and retention subcommittee. This subcommittee is focusing on improving retention in three high schools, targeting the incoming freshmen.

- One of the four goals of the New Orleans economic development committee is to develop the human skills and capacities in the community. Strategies include coordinating the training programs that currently exist, creating family learning centers for computer-assisted instruction in basic skills, and creating scholarships for basic and vocational education.

**Creative strategies are required to fund economic development.**

Since Healthy Start did not allocate any funds directly to economic development, staff need to be especially creative in attempting to fund it. The New Orleans strategy taps into many sources, such as the Jobs Training Partnership Act, local foundations, state funds, and other federal agencies. Private sources have also been identified to provide venture capital loans to potential businesses.





## Looking Toward the Future

Throughout the stages of the projects—the planning, development, and implementation of programs—the Healthy Start consortia have looked toward the future and considered the long-term implications of their efforts.

All consortia must contend with the evolution of their role. The consortia were constituted during the planning phase, when there was a tremendous amount of work to be done in translating a needs assessment into a comprehensive plan for Healthy Start in the community. Members of the consortium were involved in brainstorming about possibilities and trying to create the best opportunities. As one member of the Baltimore consortium said, “The early days were exciting. We were grappling with what we could do, feeling like the sky was the limit.”

Now that the consortia have moved into the implementation phase, the responsibilities of the members are less clear. A member of the Pee Dee consortium believes that “the most important work of the consortium is to follow up and provide technical assistance.” While most members would understand the impor-

*“The early days were exciting. We were grappling with what we could do, feeling like the sky was the limit.”*

tance of monitoring and providing course corrections, the actual mechanics of how to do that are less clear.

At this point, it is much too early in the process to determine how effective the consortia are in mobilizing the community to reduce infant mortality. The effects of community organizing may not be felt for many years. One way to assess the effectiveness of the consortium, however, is to ask: "How do others in the community see the Healthy Start consortium?"

- One member of the Northwest Indiana consortium noted, "We are viewed as a successful network in the community, which enhances the potential to elicit additional funding to expand the program." For example, the Centers for Disease Control and Prevention wants to establish a center to provide immunizations through their network.

A critical concern for all the consortia to consider is the question of what will happen after the federal Healthy Start grant ends.

**Those consortia that have the longest view, and that look both backward and forward in time, also tend to have the broadest view.**

Those who have the experience to look back at the programs of the 1960s and the 1970s, and the ability to envision the future, are concerned with many other issues besides the specific interventions that will draw women into prenatal care. Every step of the program is measured against the question: "And what will happen after funding ends?"

- The New Orleans consortium has been concerned about what happens "after Healthy Start" even before the city was awarded the grant. Historically, enough programs have come through the community without leaving an apparent legacy that Healthy Start wanted to make sure that its efforts were directed toward the long term. This long view has kept the focus on the legacy of Healthy Start in the communities, and has meant that energy and resources are devoted to community organizing and economic development. New Orleans Healthy Start has also sparked some systemwide changes (separate from its own efforts) that will be sure to outlive the program, such as a Perinatal Task Force that examines the issue of changing the medical model used to provide care in the city.
- Northwest Indiana is in a special situation because the Northwest Indiana Health Department Cooperative has a special jurisdictional status, and it may be eligible for special tax status.

Most of the sites believe that the program will be so effective that someone will fund it even after the five-year period is over. Many believe that their consortia have found a new way of operating in the community, so that they will continue regardless of federal funding.

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## **Recommendations to enhance Healthy Start consortium development**

The local Healthy Start consortia identified several actions to foster collaborative efforts.

1. **Bring together all those involved in Healthy Start programs who are working on developing the consortia and the local councils as part of a national "community summit" meeting.** At the very least, those already working on these issues in the various communities should be brought together to discuss their concerns and strategies. Consumers and activists need to be part of that discussion; they are the individuals involved in the frontline of community organizing.





2. **Provide information on other efforts in collaboration and community organizing.** There are many other collaborative efforts occurring around the country which might have lessons for the Healthy Start Initiative. Disseminating this information on a regular basis would be helpful. It would be even more valuable if opportunities were created for Healthy Start staff to meet with some of the leaders of these other efforts, either through visits to their communities or through attendance at national conferences that deal with these issues.
3. **Provide help for training staff and community members in coalition building and community organizing.** Healthy Start staff and consumers need training in building coalitions and organizing their communities.

The federal Healthy Start Initiative could either fund training slots in other organizations' existing training programs or create a training program specifically for Healthy Start. Either way, staff and consortium members at all levels should be involved. Leaders of the local councils as well as leaders of the project consortia could benefit from training. Consumers also need to be part of the training.

4. **Identify resources for collaboration and community organizing.** Community organizing and consortium development is one of the most underfunded aspects of Healthy Start. The central office could identify other sources of funds for these activities, either in other departments such as housing or labor, or in foundations. As a member of the New Orleans Healthy Start consortium requested, "The federal Healthy Start office could contact progressive foundations and open the door for us. If they do the research as to the foundations that might be interested in funding this type of work and make the initial contacts and screening, we can do the rest. We can even help other Healthy Start sites with grant writing if they need it. We need the information as to who would be interested in being partners with us and financing us."
5. **Provide funding for economic development. Federal policies could be changed to permit revolving funds to be established, or Healthy Start could assist in tapping into other funding sources.** Even a revolving fund would give fledging businesses access to needed seed money. Two critical features of starting up a business—creating business plans and advertising—can be the most difficult to fund through other sources.
6. **Assign one staff member at the national level to consortium building and community organizing.** If building an effective consortium is as important to Healthy Start as the guidance suggests, the central Healthy Start office should also devote some of its resources to the issue. One staff member could be responsible for implementing the other recommendations on collaboration. This staff member could channel information about other collaborative efforts and potential sources of funding to those working on the issue at the local level.

# Appendix A

## Healthy Start Sites Visited

### Chicago Project

Site visit: September 16, 1993

With the Illinois Department of Health as the grantee, the Chicago Healthy Start Initiative has established a locally based comprehensive service system in six inner-city neighborhoods. To reduce the area's infant mortality rate, the Healthy Start team believes that it must create a process for empowering the community while establishing comprehensive systems of care for residents. Strategies such as presenting workshops for community organizations and providing child care and transportation to consortium members facilitate the mobilization of the community and its feeling of ownership of the program. The community has helped design Healthy Start's comprehensive case management system. It coordinates services for pregnant and/or parenting women, particularly those who are homeless, incarcerated, ex-offenders, and substance abusers. In addition, the Initiative supports a family resource center which provides culturally sensitive perinatal services at a community-based Hispanic organization. Healthy Start resources have also allowed federally qualified health centers to provide enhanced perinatal care and family planning services to project area residents. By 1996, the Initiative aims to reduce the area's infant mortality rate, 19.6 deaths per 1,000 live births (1984-88), which is nearly twice the Illinois rate.

### Northwest Indiana Project

Site visit: September 17, 1993

A unique entity was created to manage this Healthy Start Initiative: the Northwest Indiana Health Department Cooperative. This new organization was created to administer comprehensive services aimed at reducing the high infant mortality rate in the four cities of East Chicago, Gary, Hammond, and Lake

Station. Because of its unusual structure, the cooperative recognizes the need to cross geographic, service area, and public agency barriers to provide services—efforts that need to be coordinated and user-friendly. In each of the cities, relationships are forming to provide health education, child care, transportation and social services coordination, case management, home visiting, and financial counseling. The Healthy Start team works to strengthen an active physician network and create contractual provider agreements for services. Because this area has a high rate of teen pregnancy, some efforts are specifically targeted to teens. For example, a family relations class sponsored in conjunction with a local college focuses on parenting skills, self-esteem issues, conflict management, and education/career goal setting for both female and male teens. The 1984–88 baseline infant mortality rate for this area was 16.2 deaths per 1,000 births.

### **New Orleans Project**

Site visit: October 11–12, 1993

Locally referred to as Great Expectations, the Healthy Start Initiative in New Orleans serves an inner-city area. Great Expectations is managed by the New Orleans Health Department but is built on partnerships between communities, churches, health care advocates, providers (such as community and migrant health centers and Excelth), and government agencies. The Initiative uses a holistic approach to help people change factors which place them at risk for poor pregnancy outcomes. The health care system is improved by dedicating resources to community-based perinatal services, providing case management to high-risk women, and encouraging greater coordination among providers. Great Expectations has enlisted the support of community residents as outreach workers to bring pregnant women and infants into the system. To involve the entire community in the project, Great Expectations sponsors an African American training and orientation program (Communiversities) and promotes broad-based community participation in working to solve the infant mortality problem. Finally, Great Expectations educates the entire community about the importance of prenatal care, proper nutrition, and family planning through a public information campaign. The work of the Initiative should change the high infant mortality rate of 23.3 deaths per 1,000 live births (1984–88).

## **Baltimore Project**

Site visit: September 15, 1993

Managed by the Baltimore City Health Department, this Healthy Start Initiative addresses needs in a project area that encompasses two-thirds of the city, with two target areas selected for intensive intervention. When assessing needs, the Healthy Start team found that health and social services were available, but a variety of barriers prevented consumers from accessing them. Therefore, the Initiative seeks to make prenatal and pediatric care more user-friendly by reforming the way medical services are provided. For example, providers are encouraged to decrease waiting times, provide continuity of care, offer more courteous and sensitive staff, encourage male involvement, and improve physical settings. Neighborhood Healthy Start centers in the two target areas also provide a core set of services, including risk assessment and case management of clients; on-site eligibility for benefits such as WIC and Medicaid; health education; and housing services. Child care and transportation help clients access on-site services, but the centers also conduct intensive outreach and home visiting. The Initiative educates the entire community through major outreach and education efforts aimed at non-pregnant women and their families. Through these efforts, the initiative hopes to reduce the area's high infant mortality rate of 20.1 deaths per 1,000 live births (1984-88), which is higher than that for the city as a whole, and among the highest of large U.S. cities.

## **Pee Dee Region Project**

Site visit: September 2-3, 1993

Six rural counties in the northeast corner of South Carolina—all of which are classified as medically underserved areas—form the Pee Dee region. The United Way of South Carolina is the grantee for this Healthy Start Initiative, which aims to reduce infant mortality by ensuring that health and ancillary care is universally available and culturally acceptable. Establishing Rural Outreach, Advocacy and Direct Service (ROADS) teams in each county is one of the strategies used to meet this goal. Recognizing that many households in the region do not have automobiles, Healthy Start uses these mobile teams to deliver outreach services to women and infants, providing prenatal and infant care, health education, case management, and substance abuse services. The Initiative enhances the efforts of local

providers (i.e., through funding for equipment upgrades and satellite locations) and community health centers. To address the special needs of adolescents, Healthy Start is implementing six Teen Life Centers, where activities such as adult mentoring, career counseling, health education, and referrals to other services are sponsored. A scarcity of medical providers in the area, a long-standing problem, is being addressed through aggressive attempts to recruit providers. Successful implementation of these activities should result in a reduction in the area's base-line infant mortality rate of 16.1 deaths per 1,000 live births (1984-88).

# Appendix B

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