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ABSTRACT

This volume describes the experiences of each of the 15 rural and urban Healthy Start initiatives. These projects were set up in areas that had infant mortality rates that were 1.5 to 2.5 times the national average. Project locations include major cities such as Chicago, Illinois; Boston, Massachusetts; and Oakland, California, and rural areas in South Carolina and the Plains states. The projects brought together families and community organizations to design and implement new procedures in an intensive effort to reduce the infant mortality rate in their communities by one-half within 5 years. In this report, representatives from each of the projects share the lessons they learned in planning and implementing the Healthy Start initiative to reduce infant mortality. While some speakers discuss unique aspects of their programs, many stress common themes. Recurrent themes in the reports include community involvement, consortia development, management and governance, program initiatives, provider issues, and sustainability. These themes are outlined in the executive summary at the beginning of the volume. (:AC)

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Early Implementation Lessons Learned

Volume II

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Volume II

Early Implementation: Lessons Learned



Volume II

Early Implementation: Lessons Learned

Edited by

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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.

At the 1993 Healthy Start grantee meeting, representatives from each of the 15 Healthy Start projects shared their "lessons learned" in planning and implementing the Initiative. Early Implementation: Lessons Learned is based on these presentations. Because of the widespread interest in learning about Healthy Start and what the projects have done to effectively impact on infant mortality, this publication is part of a planned multi-volume series The Healthy Start Initiative: A Community 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. The first volume of the series, Consortia Development, was published in Spring 1994. Other volumes being considered for future publication include The Dos and Don'ts of One-Stop Shopping and What Works.

Thurma McCann, M.D., M.P.H.
Director
Division of Healthy Start
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Executive Summary

The Healthy Start Initiative began October 1, 1991, with 15 projects which were all given the opportunity to bring together families and community organizations to design and implement new procedures in an intensive effort to reduce the infant mortality rate in their communities by one-half within five years. By November 1993, teams in each of the 15 Healthy Start sites had begun to learn how to identify needs, involve the community, work with consortia, establish and manage an array of program initiatives, and evaluate their efforts. These teams—including consumers, consortia members, and staff—were eager to share their experiences with others. The 1993 Healthy Start grantee meeting, held November 4–6 in McLean, Virginia, gave representatives from each project the opportunity to present and share with each other the lessons they had learned.

The presentations given at this meeting provide the basis for this publication; they appear here in the same order as they were given. The lessons learned through the projects and shared by project representatives are marked by a star (③) in the text. While some speakers discussed unique aspects of their programs, many stressed common themes. Recurrent themes included community involvement, consortia development, management and governance, program initiatives, provider issues, and sustainability. Some of the speakers shared messages of hope that applied to all aspects of Healthy Start.

Community involvement

Involving the community is a critical Healthy Start goal. Speakers presented a variety of methods used to encourage and sustain community involvement.

Recognize culture and class differences. Working with and serving the community requires an appreciation of differences:



- Be sensitive to culture and class differences. Consider cultural aspects when implementing programs in minority communities.
- Examine policies, practices, and procedures for racial, gender, and age bias.

Identify community needs. Healthy Start teams stressed the importance of working with the community when assessing needs for appropriate program planning:

- Ask the community to identify its problems, concerns, and needs. Do not assume that the priorities of project leaders are necessarily the priorities of community members. In an area with high unemployment and inadequate housing, families may not see health care as a priority issue. These other issues must be dealt with before prenatal and pediatric care can be fully addressed.
- Trust the community: It knows what it needs, and how to solve its problems. Ideas and suggestions from focus groups can be outstanding. Staff should use these ideas to create effective programs.

Involve the community in planning and implementing programs. It is also critical to involve the community when planning programs:

- Build on existing community-based resources, and involve the community and its resources in planning and implementation.
- Encourage grassroots participation and involve the community early in the process of setting up programs. Time and effort are needed to develop and sustain community involvement. Allow for this additional time when mapping the program's major activities and objectives.
- Maintain a dialogue with the community, even if the process is frustrating.
- Make a commitment to involve the community integrally in the process of developing tools such as case management manuals.

Employ community members. A good way to ensure community involvement is to hire community members for Healthy Start programs:



- Take advantage of the special skills of community members through programs such as Resource Parents (outreach workers), in which clients receive assistance from trained members of their own community.
- Use community development specialists from the community to help link the Healthy Start Initiative with existing community groups and agencies. The specialists' familiarity frequently facilitates open communication and expedites collaboration with the community groups.
- Work with experienced community organizers, who can help diffuse many problems before they become disruptive to the program.

Ensure community empowerment. Healthy Start teams want to involve communities in this Initiative, but they also want the communities empowered to address other issues in the future:

- Recognize that community empowerment is necessary to combat community problems. Often, the community does not realize all of its resources.
- Empower communities through seed funding, but do not expect that these funds will guarantee success. Initiate community empowerment toward reducing infant mortality by providing funds so that groups can begin providing needed services. Funds should be given with a string attached: the expectation that the groups will actively participate and collaborate with other community agencies to maximize existing resources.
- © Encourage government agencies to give power to the community. It is important for government entities to decentralize grant awards and enable community-based organizations to take charge when appropriate. While difficult, this process is important and has a critical long-term impact on the project and the community.
- Stress equality of power sharing; there can be no empowerment without ownership. Throughout the consortium and the community, Healthy Start teams emphasize that consumers and providers have an equal voice in planning and implementing programs, and that both are responsible for the project's successes and failures. Healthy Start teams strive to nurture this equality.



Too often, providers control the programs while consumers do not participate because they sense that others do not listen to them or follow their directions.

• Learn the meaning of sharing power through participatory leadership, consensus building, and collective responsibility.

Consortia development

Individuals and organizations from many sectors of the community make up the consortium at each Healthy Start site. Consortia help design and implement services and encourage community flexibility and ownership of the Initiative. Consortia Development, the first volume in the series The Hea hy Start Initiative: A Community Approach to Infant Mortality Reduction, describes the early development of five Healthy Start consortia. At the 1993 grantee meeting, many speakers from the other 10 Healthy Start projects also discussed the lessons they had learned in participating on or working with their consortia.

Develop consortia membership. Recruiting members and adapting to change were important issues for Healthy Start teams:

- Choose collaborative partners carefully. Who should be involved? What is needed from partners?
- Involve consumers, elders, and community members in the consortium.
- Minimize agency representation on the advisory cour.cils. Meetings should not be top-heavy. Most often, no more than two people from the same agency are members of the same advisory council.
- Establish governing bodies that reflect the ethnic composition of the community.

Develop effective partnerships. Speakers presented lessons learned about innovative ways to develop valuable partnerships:







- Find good partners by identifying organizations that have mutual goals. A good partner actively shares fiscal and programmatic concerns.
- Coordinate services with other organizations, local colleges or universities, and other local, state, and federal programs to conserve and expand resources, facilitate access to services, and integrate systems.

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• Recognize that agencies must work together to survive and to fulfill community needs.

Develop consortia leadership. Along with recruiting members for the consortia, Healthy Start teams were concerned with recognizing and developing leadership in these groups:

- Ask the community who their leaders are when looking for community representatives for Healthy Start consortia.
- Recognize that consortium building is a dynamic process, and that early consortia may change considerably; the consortium's leadership must have tolerance and adaptability while keeping the group goal-directed.

Facilitate consortia participation. To be active, vital contributors, consortia need support from Healthy Sta*t:

- Pay focus group participants for their time and effort.
- Allot funds to support community participation; for example, fund activities such as transportation and child care.
- Vary the settings of meetings and ensure that community members are not intimidated by the meeting location. If it is difficult for members to attend meetings because of location, valuable time and effort will be wasted.

Management and governance

Reflecting on their early efforts, Healthy Start representatives were eager to share their vision for the Initiative; they were also willing to provide details about specific management and governance issues.

Prepare well before beginning work. Many speakers described difficulties encountered when programs were started too quickly. These experiences taught the teams to prepare well:

O not start before the team is ready to begin—think through projects fully before beginning to work. Community groups are eager,



- but they may lack expertise; Healthy Start staff will need to work closely with the community. Do not spend money that you do not have. Do not commit to programs until funding is guaranteed.
- Codify working relationships so that future problems can be addressed by examining agreed-upon principles. Describe an equitable relationship between the community and the grantee on paper.
- Set realistic time frames.

Address funding issues. Healthy Start leaders wanted to award contracts to community-based organizations, but found that staff first needed to work closely with these groups before sending out requests for proposals (Ri*Ps):

- © Conduct preproposal orientations with community groups when ilocating funds for community activities. Involve the community actively from the beginning. *before* RFPs are disseminated. Offer technical assistance to all agencies and organizations—especially community-based organizations—planning to respond to RFPs.
- © Be prepared for increased tension when grant monies are being distributed. Relationships among members of a collaborative group may become more strained when dissemination of money is involved.

Implement appropriate personnel policies. In the process of recruiting, training, and managing staff, Healthy Start teams learned about working with a diverse group:

- Recruit and place permanent staff quickly.
- Assess the problem-solving skills of candidates for staff positions. and recognize that people without a high school education or a GED may perform as well as (or better than) those with formal education credentials.
- Use multidisciplinary case management teams to provide comprehensive services. Be prepared for challenges when coordinating these teams; issues of role definition, and of how roles relate to each other, become important.
- Hold meetings across disciplines and keep staff informed of program activities in other sectors. Various staff members who provide services to the same client should be aware of each other's work.



Place highly skilled managers in supervisory positions, especially when staff from the community do not have substantive working experience.

Emphasize monitoring. Ongoing monitoring was a recurring theme. Speakers discussed the importance of monitoring specific programs, particularly when the programs played a critical role in achieving the project's goals and objectives:

- Realize that effective project management and accountability are critical to the success of the program.
- Make quality assurance a high organizational priority.
- Address the user-friendliness of clinics by working directly with service providers to change clinic policies and characteristics.
- Ask consumers what they think of the services being provided. Using techniques such as focus groups, a team can discover important barriers to the effective use of services.
- Tailor data tools to the specific needs and circumstances of a community.
- Consider the ramifications of providing intensive services to a few people, compared to providing less intensive services to a larger group.
- Recognize that collaboration takes time and hard work, and that it can be difficult to turn over services to the community if its members do not understand global issues, especially the need for data collection.

Unique program initiatives

Healthy Start representatives presented information on a wide array of program initiatives. In particular, speakers shared lessons learned from implementing outreach programs, integrating services, and involving men in Healthy Start services.



Find clients through outreach to the community. Many Healthy Start sites conduct intensive outreach efforts to find clients in need of services:

- Explore nontraditional ways of finding clients. The most needy clients may never seek out services at a Healthy Start site, so Healthy Start consortia and staff undertake proactive means to find these individuals. Outreach includes door-to-door canvassing, outstationing, and involvement of community churches and schools.
- Establish procedures for referrals from outreach to clinical services. Beware of "out of sight, out of mind" and ensure that clients referred for services actually receive those services.

Recognize the special needs of outreach workers. Many Healthy Start teams draw from the community when recruiting outreach workers. These workers bring special skills to the position, but they may have special needs:

- Seek community input when recruiting community outreach workers, but maintain control over the process.
- Recognize that skill levels differ among outreach workers, and plan their training accordingly. These outreach workers face a myriad of problems and environments.
- Coordinate care and integrate job arrangements and support systems for both clients *and* outreach workers.
- Plan and provide extensive training to certify community workers whenever possible, and assist and encourage them to complete GED training and/or earn degrees.

Integrate services. Healthy Start teams stressed the importance of integrating both existing and new services:

- ☼ Integrate services to reduce costs and expand resources. For example, integrate and co-locate Healthy Start and WIC/Nutrition services to maximize participation and use resources effectively. Improve the timeliness of early enrollment in prenatal care and food distribution.
- Offer multiple services at one location to encourage clients to use a variety of available services.



Involve men. Many Healthy Start services are designed to serve pregnant women, but Healthy Start representatives urged programs to include men in their plans as well:

- Target programs to *both* males and females, fathers and mothers. "Dads have babies, too."
- Encourage male involvement in a variety of ways; for example, make copies of Sports Illustrated available in the waiting room and display pictures on the wall with positive images of men who are supportive of women and their babies.
- Require the male partner to participate in one prenatal visit and two well-baby care visits during the first year.

Develop and implement incentive programs. Speakers described many program initiatives at the grantee meeting. While many programs were designed to meet specific community needs, many lessons remain to be learned about successful efforts that could be replicated elsewhere:

- © Conduct public health education in communities to connect local health providers to the community and to educate residents. Find innovative ways to educate clients and providers about services available in the community. On-line technology is one way of providing both clients and providers with up-to-date information.
- Develop and maintain a 24-hour hotline for moms, potential moms, friends, and family members in languages appropriate to communities.
- Distribute newsletters to share information (and lessons learned) with all involved with Healthy Start.
- Provide meals at clinics as an incentive to encourage mothers to come to the centers.
- Provide on-site child care, with age-appropriate activities available. Child care makes a "big difference," by allowing more private time for the client and the provider and by decreasing the level of noise and chaos in the reception area. Providing child care simultaneously removes an important barrier to accessing services while providing an opportunity for child development assessment and counseling.

- Facilitate and deliver needed services, such as education and family support services, to incarcerated women, and link them with Healthy Start services after their release.
- Focus on adolescents: work within schools, and explore and guide maturing attitudes regarding self-development, self-esteem, and parenting through activities such as poetry writing, theater groups, and peer and focus groups.
- Sponsor farmers' markets coordinated with WIC services as a way of offering quality, affordable produce to the community.

Provider issues

When assessing community needs, many Healthy Start projects discovered that there were insufficient numbers of providers of medical services in the project area. Some found that relations among providers and between providers and the community needed improvement. Many Healthy Start grantees are learning how to address these issues, in some cases, by directly providing medical services.

Increase provider supply. Many Healthy Start sites share a common concern: an inadequate supply of providers of medical care. Speakers from both rural and urban areas had gained insights about this issue:

- Build provider capacity to achieve the goal of establishing comprehensive services. Plan to spend resources not only on recruiting providers, but also on building the infrastructure needed for service expansion. Increasing medical staff does not automatically result in increased care capacity for health centers that have been poorly funded or poorly utilized in the past.
- Use creative, collaborative campaigns to recruit and retain health care providers in underserved areas. Use both long-term and short-term methods to increase the supply of medical providers. One effective method is to seek an ongoing linkage with a medical school or university offering training in multiple health professions.

Facilitate linkages among providers. In addition to recruiting new providers, Healthy Start teams help current providers work together:



- Establish linkages among providers so that they learn about common concerns and overcome fears of losing a client population. Even though extensive paperwork may be needed to establish these linkages, the communication is essential and the resulting collaboration is productive.
- © Encourage providers to move beyond networking to take risks and share resources to achieve a common goal. Sponsor orientation sessions on Healthy Start on a regular basis to accommodate staff turnover among participating resources.

Work with providers. Healthy Start teams shared concerns and suggestions developed from working directly with providers:

- © Be prepared to adjust reimbursement systems when working with nontraditional providers.
- Pay particular attention to issues of continuity of care, especially when the project area includes a teaching hospital.
- Recognize the diversity of cultural sensitivity among providers, and involve all Healthy Start providers in programs to improve their sensitivity skills.





Sustainability

The Healthy Start Initiative was originally designed as a five-year demonstration project; its goal would be reached by designing interventions that could be sustained over the long term and replicated in other communities. Some of the speakers shared ways in which their projects would have a lasting impact:

- © Establish systems that will help perpetuate the Healthy Start philosophy, even after the program ends.
- Cultivate grassroots organizations so that people will be knit together even after the funding has ended.

Messages of hope

Healthy Start staff and consortia members expressed their commitment to the Healthy Start vision through messages designed to inspire and challenge others:

- "It takes a village to raise a child."
- O "United we can make a difference and get things done."
- "Share the vision, empower the community, build a partnership, and handle conflict constructively."
- Remember the "six C's":
 - 1. Commitment (from individuals, agencies, and organizations)
 - 2. Cooperation (providers cannot assume "business as usual")
 - 3. Collaboration (work together for greater impact)
 - 4. Community (there must be community ownership of the project)
 - 5. Communication (across all levels)



- 6. Creativity (new approaches are needed to solve long-standing problems)
- Remember the "three P's": practice, patience, and prayer.
- Keep track of short-term successes and keep communities and consortia apprised of these successes; they are important motivators, and increase pride of ownership and participation in the Initiative. Recognize and honor all kinds of successes, not only the progress toward the main program goal.

The first two years of the Healthy Start Initiative have been filled with preliminary efforts to address a multitude of health-related deficiencies within these impoverished communities. There have been barriers to overcome, political changes, project staff turnovers, turf battles, and bureaucratic requirements, all of which have presented repeated challer. It to these 15 grantees. Healthy Start recognizes that a project needs time to become fully operational. Initial impressions may overstate or understate ultimate project outcomes. We share these lessons learned from our early Healthy Start experiences in the hopes that they will help other communities improve their health care systems—improvements that are needed to reduce infant mortality and address other pressing public health problems.

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CHICAGO PROJECT

Presenter: Rory Lopez

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 help to mobilize the community and encourage community ownership of the program. The community has helped design Healthy Start's comprehensive case management system, which 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 that 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. The goal of this Initiative is to reduce by 50 percent the area's infant mortality rate of 19.6 deaths per 1,000 live births (1984–88), which is nearly twice the rate for the state of Illinois.

Collaboration

The Healthy Start consortium includes a partnership between the city, county, and state. Lopez observed that it has been a learning process (and "quite a task") to bring together three different public health entities.

The state used the term "collaboration" in its application, and the process of designing the project involved collaboration with consumers and individuals at the grassroots level—but it was sometimes a difficult process. Collaboration can delay time frames for meetings, noted Lopez, who cautioned that "you might think you want to hear, but sometimes you don't want to hear" all that the participants in the process have to say. Collaboration, though tedious and time-consuming, can be valuable for all if each member of the consortium is willing to change. Lopez commented that the state realizes it has grown through this process by truly listening and by implementing concepts contributed by the community. The Chicago team's experiences in working collaboratively provided an important lesson learned:

Maintain a dialogue with the community, even if the process is frustrating.

Case management

A committee of community members works on case management issues and has developed a case management manual that will be distributed to other Healthy Start directors. Historically, a number of agencies have used case management, working from a variety of models. This manual was designed to bring together different approaches in order to develop one model for use throughout the system. In creating the Chicago team's manual, turf issues arose; at times, staff thought that it would be easier to write the manual themselves and avoid "bick-ring," However, the final product was better because the community was involved in the process. The Chicago consortium is proud of the manual because the people at the grassroots level have worked diligently to produce it. The consortium intends to seek the community's reactions to the manual and revise it accordingly.



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• Make a commitment to involve the community integrally in the process of developing tools such as case management manuals.

Using the model for case management put forth in this manual, the team provides intensive case management to a small group of project area residents. The state has a program under Medicaid entitled Healthy Moms, Healthy Kids, which provides basic Medicaid case management services (i.e., tracking of appointments), but the caseload per manager is approximately 115 clients. The Chicago consortium provides case management, but limits the caseload per manager to 40–45 clients, to create a more effective program. Through the high-intensity Healthy Start Initiative, the full impact of case management will be demonstrated. In the process, a control group will be formed comprising recipients of the low-intensity Medicaid program. The result will yield both a question which raises many other issues and a lesson learned:

Consider the ramifications of providing intensive services to a few people, compared to providing less intensive services to a larger group. Community agencies that serve clients comprehensively may be forced to turn away clients because scarce resources prevent universal coverage. These clients may be served elsewhere, but not as intensively, or they may not be served at all. As a result, a control group of eligible but underserved (or unserved) clients is created. Thus, the effect of the intensity of services can be measured by comparing outcomes between the group receiving intensive services and the control group.

Violence

Violence is an important, pervasive issue. Chicago's consortium instituted a violence reduction component based on a Hawaii program entitled Healthy Families. America. The consortium paid community members to participate in focus groups, where they read the Healthy Families manual and then advised staff and the consortium on how to revise the program for implementation in Chicago. Lessons learned include the following:

O Pay focus group participants for their time and effort.



Trust the community: It knows what it needs, and how to solve its problems. Ideas and suggestions from focus groups can be outstanding. Staff should use these ideas to create effective programs.

In this case, community input led to program modifications. For example, in the Hawaii Healthy Families program, workers began implementing the violence reduction program by visiting mothers in the hospital after delivery. Chicago community members stressed the importance of beginning the program before the mother enters the hospital, so that a relationship based on trust can be established.

Lessons of hope

The first year was spent designing the program, which is currently being implemented. Lopez had heard that Healthy Start might be extended for one year; he would also support a two-year extension. He concluded with a final lesson learned:

• "United, we can make a difference and get things done."





DETROIT PROJECT

Presenter: Wilhelmina W. Giblin

The Detroit Healthy Start Initiative believes that the project area's high infant mortality rate (26.3 deaths per 1,000 live births) is due in great part to poverty and related social and economic conditions. Through the Healthy Start effort, which is directed by the Detroit Health Department but operated in close coordination with the local consortium, resources will be directed toward the chronic problems associated with poverty. The community plays a central role in determining project priorities and services provided; community development activities foster this role. To coordinate services, the Initiative relies on an interdisciplinary team of professionals and paraprofessionals, one of whom acts as a case manager who can link a client with a variety of services. A special "inreach" program links agencies with socially isolated clients during their postpartum hospital stay. Enhanced pediatric. adolescent, obstetric, and family planning services are offered at two health department sites. A planned management information system will link services with clients, and service providers with one another. The goal of this Initiative is to reduce the area's infant mortality rate by 50 percent by 1996.

Outreach

The Detroit consortium found that clients do not always arrive at the door of a service agency, even though they may need services. The consortium stresses the importance of extensive outreach.

Several outreach mechanisms were used, including door-to-door canvassing, outstationing, and health fairs. Outstationing was accomplished by placing workers at Social Security sites during peak periods to educate people about services. The first health fair—attended by 1,000 people—provided family planning, immunizations, and HIV testing. More than 40 pregnant women were identified for follow-up through Healthy Start. The atmosphere was funfilled, and people perceived that they had received quality services in a non-threatening situation. Three health fairs have been held, each drawing nearly 1,000 participants.

• Explore nontraditional ways of finding clients. The most needy clients may never seek out services at a Healthy Start site, so Healthy Start consortia should undertake proactive means to find these individuals.

Case management

The Detroit consortium works with clients to help them identify their needs and concerns, rather than having professionals identify client needs. Healthy Start teams have been expanded to include representatives from many disciplines, including social work, nursing, and mental health. Lessons learned from this experience include the following:

- Use multidisciplinary case management teams to provide comprehensive services. Be prepared for challenges when coordinating these teams; issues of role definition, and of how roles relate to each other, become important.
- Encourage ongoing staff development, case conferences, and regular staff meetings to help all members of a multidisciplinary group work as a team. Information about clients can be



shared at case conferences, and strategies for working with members of other disciplines can be identified at meetings.

Community empowerment

The Detroit consortium learned many lessons about working with communities, including how communities prioritize their problems.

• Identify the issues that community members really see as problems. In an area with high unemployment and inadequate housing, families may not see health care as a priority issue.

In the project's early stages, when requests for proposals (RFPs) were published to explain what money was available, no orientation was provided to help consumers with the process of applying for funds. Community members, who did not know how to write proposals, had difficulty fulfilling RFP requirements. The consortium realized that more aggressive announcements about proposals were needed:

- Involve consumers early in the process.
- Conduct preproposal orientations with community groups when allocating funds for community activities.

The consortium gained valuable experience in community empowerment by working with advisory councils. Three councils were established to help identify important issues, but collaboration did not come easily. Strategies to increase community involvement include the following:

- Ask the councils whether the location of meetings is a problem. If it is difficult for members to attend meetings because of location, valuable time and effort will be wasted.
- Minimize agency representation on the advisory councils. Meetings should not be top-heavy.
- © Keep the goal in focus. For example, one advisory council discussed conducting adult health screenings, but the goal of the Healthy Start program is to reduce infant mortality. High



cholesterol may be a problem, but it should not be addressed through Healthy Start.

Management and governance

The consortium sought to integrate a variety of services and organizations, including the grantee (city of Detroit), outreach (conducted by Wayne State employees). and clinical services (nurse-midwives and pediatricians at Healthy Start sites). Following are the lessons learned through this process:

- © Establish procedures for referrals from outreach to clinical services. Beware of "out of sight, out of mind" and ensure that clients referred for services actually receive those services.
- O Hold meetings across disciplines and keep staff informed of program activities in other sectors. Various staff members who provide services to the same client should be aware of each other's work.

Careful planning is critical. At first, the team was overzealous about moving into service provision when it did not yet have the capacity to provide the services. For example, a community group wanted to sponsor a health fair, so the group ordered materials before determining who would perform the examinations, where the examining rooms would be set up, and other important details. The group had to cancel the proposed fair, thus learning an important lesson:

• Do not start before the team is ready to begin—think through projects fully before beginning to work. Community groups are eager, but they may lack expertise; Healthy Start staff will need to work closely with the community.

The Detroit consortium struggles with the difficulties of administering a huge program. Supervising and scheduling staff members can be difficult when they come from different personnel systems. Differing levels of benefits can create ill feelings among staff. An important management lesson follows:

• Integrate systems to reduce disruption, and consider how benefits will be determined when staff come from multiple systems.





CLEVELAND PROJECT

Presenter: Katherine Woods-Erwin

Managed by the Cleveland Department of Public Health, this Initiative seeks to reduce the project area's infant mortality rate by working collaboratively with an array of people and institutions-health care providers, social and support service agencies, consumers, educators, researchers, and public and private leaders. Reaching clients through outreach workers has been one of the Initiative's most important efforts. This community-based outreach program links women, adolescents, and their partners to early and continuous care. Among other activities, the outreach workers link clients with providers: track appointment compliance; and help clients access Medicaid, Special Supplemental Food Program for Women. Infants and Children (WIC). job training, and parenting programs. The training program for the outreach workers includes components such as Working with Male Partners, and Children and Violence. Healthy Start staff work with providers to ensure that comprehensive primary health care, multidisciplinary assessment, and social services are offered. In addition, a public information and education campaign educates the community about the project and the importance of early entry into prenatal care. All of these efforts are directed toward improving the health of inner-city residents-many of whom live in poverty-and achieving a 50 percent reduction in the city's infant mortality rate of 21.3 deaths per 1,000 live births (1984-88).

Outreach

The Healthy Start consortium consolidated the 16 social planning areas into 10 neighborhood service areas in order to collect demographic and psychosocial indicators on clients. To help integrate services, outreach sites were placed at sites where other services are provided, such as neighborhood centers, hospitals, and Salvation Army locations.

The Cleveland team has learned many lessons as it has developed its out-reach program. One lesson concerns the importance of partnerships. Through a collaborative effort with the Job Training Partnership Act (JTPA) and the Supplemental Employment Program, the consortium conducted a centralized, eight-week classroom training program for outreach workers. These programs, which provide a transition between welfare and work, subsidize employment and allow most participants to retain Medicaid services, child care services, and food stamps for one year. From this effort, the team learned to:

Seek out partnerships with other local, state, and federal programs. Working closely with other initiatives can help projects accomplish goals.

The team also learned cautionary lessons—one concerning the administration of the program. The consortium thought it would receive a Medicaid waiver in Ohio for case management and outreach. However, a change in administration at the state level created new problems, underscoring the following lesson:

• Track changes in government administrations; they may affect Healthy Start Initiatives.

The team is currently exploring options for an administrative case management waiver and for alternative methods of funding the project beyond the five-year period.

Outreach workers

Cleveland's Healthy Start consortium trained more than 200 outreach workers (more than 140 of whom are currently working for Healthy Start)



Some are taking the GED examination and others are taking college-level classes. There is an institutionally based career ladder for outreach workers who demonstrate outstanding skills.

• Recognize that skill levels differ among outreach workers, and plan the program accordingly.

In the second year of Healthy Start funding, the Cleveland site did not receive the amount of money needed to train the number of outreach workers that the consortium wanted to train. After the notice of grant award, the planned number of outreach workers had to be reduced. The team learned the following lesson from this experience:

• Do not spend money that you do not have. Do not commit to programs until funding is guaranteed.

Woods-Erwin described the "high level of commitment" of some of the outreach workers in the Cleveland project. Workers exemplified this commitment by making their personal telephone numbers available. riding the bus with clients, and reaching into their pockets to help clients when necessary. Community residents can make a difference:

Stress a "bottom-up" approach. It can work with truly committed and motivated outreach workers.

However, outreach workers often face the same problems as clients. Continuing education sessions for both clients and outreach workers can help. The consortium has learned that it needs to:

• Coordinate care and integrate job arrangements and support systems for both clients and outreach workers.

Outreach workers employ a variety of techniques to identify the target population, such as going to the public schools during lunchtime to disseminate information and act as a reference point for clients.

• Outreach should include door-to-door canvassing and outstationing.



Community empowerment

Although communities can become isolated, they can also be united by an interest in a common issue. In Cleveland, residents successfully championed a campaign against the spoiled meat sold in several grocery stores in the Healthy Start communities. By addressing an issue en masse, the residents were able to do something about it—thus empowering the community.

© Community empowerment is necessary to combat community problems. Often, the community does not realize all of its resources.

The Healthy Start Initiative has helped community members become more actively involved in working toward community goals.

The committees of the Cleveland consortium meet monthly. However, Woods-Erwin agreed with Giblin (Detroit) that it is difficult to keep consumers actively involved in Healthy Start. Neighborhood coordinators help motivate community involvement. Recently, two community organizers were hired to aid in recruiting.

Time and effort are needed to develop community involvement.

Successes

Even if Healthy Start teams do not meet the goal of a 50 percent reduction in infant mortality, there will be other successes—and they should be documented. Integration of services is a success for the Cleveland project, and the consortium plans to track others:

• Keep track of short-term successes.

In addition, to help reach goals, consortia should learn from other programs. It is important for people from Healthy Start sites to share information about strategies used at other sites. Woods-Erwin visited three other Healthy Start sites and modified some Cleveland activities according to the lessons learned from those sites.

• Learn from other Healthy Start projects and consortia.



QUESTION AND ANSWER PERIOD

Rewarding community outreach workers

A member of the audience spoke about the importance of examining policies for appropriately compensating community workers. Healthy Start Initiatives can "reward staff with degrees" but need a "comparable way of rewarding staff doing great work" in the community. Since health professionals are less likely to go into the heart of 'he communities, community health workers showing a different level of commitment should be rewarded for their efforts.

Documentation and evaluation

This same member of the audience then turned to the issue of documentation and evaluation, noting that, while it is important to state objectively the impact of the programs, it is also important to consider the ramifications of the methods used in conducting these evaluations. Healthy Start programs are geared toward empowering disenfranchised, underserved communities, but "we're really doing a lot of invasive kinds of things in trying to document how effective our interventions are." Making "direct links" between interventions and people can be problematic in underserved communities; this strategy can come into direct conflict with the theme of empowerment.

Alternative ways of collecting data should be discussed. Is Healthy Start truly empowering these communities when "we're still invading their lives" to gather the data needed for the project? The grantees agreed that dealing with these issues is difficult and troublesome.

Listening to community members

Directing a question to Wilhelmina Giblin, the audience member commented that it is important to listen to all that the community has to say, including subjects that Healthy Start staff may perceive as tangents. If staff do



not "properly address" issues important to the community, the community "won't listen to us." Many factors have an indirect impact on infant mortality, and should be considered in the overall effort to reduce the infant mortality rate. Giblin followed up by describing an incident in which it might be appropriate to redirect community energy: community members had proposed conducting general health screenings, but hospitals in the community already sponsored health screenings without offering maternal and child health services (including pregnancy tests). Giblin explained that it would be better to avoid duplication of resources, and to concentrate, instead, on the target population.

Empowerment

A member of the audience expressed concern with the term "empowerment." and asked the panel what kinds of things they were doing to empower communities and prepare them for the time when federal funding ends. Lopez (Chicago) shared a few examples which illustrate the following principles:

- Certify community workers whenever possible, and encourage them to earn degrees.
- Cultivate grassroots organizations so that people will be knit together even after the funding has ended.

Another member of the audience observed that communities should learn how to manage their own programs so that they acquire the skills for future projects. It is also important to teach community members how to write , grant proposals.

THE HEALTHY STARY INITIATIVE



PHILADELPHIA PROJECT

Presenters: Deborah Fisher and Amy Levi

The Philadelphia Healthy Start Initiative is a broad-based cooperative effort of community groups, health care providers, local government, and other concerned groups and individuals working to reduce infant mortality in west and southwest Philadelphia. A variety of neighborhoods comprise this inner-city area, including relatively affluent, multiracial communities; neighborhoods that are predominantly African American; and a growing immigrant population (Haitian/Liberian). The Division of Maternal and Child Health, Philadelphia Department of Public Health, directs this project. Healthy Start capitalizes on the existing infrastructure of health providers and community organizations to provide a range of psychosocial, educational, outreach, and individual and community development services. Highlights include a far-reaching public/consumer awareness campaign; collaborative meetings and formal agreements among Healthy Start participants that strengthen linkages between the community and clinical providers; education about teen pregnancy through the Adolescent Peer Power Program: outreach efforts, particularly through home visiting; mobile services, using a van to provide outreach, education, and referrals; and improved physical settings in clinical sites. In addition to its special activities, the Initiative addresses issues of capacity, structure, and content of health care service in the perinatal care system; for example. Healthy Start supports expanded evening and Saturday clinical service hours at clinic sites. Through these concerted efforts—and the critical involvement of the community—the Initiative hopes to reduce by 50 percent ' project area's infant mortality rate of 22.3 deaths per 1,000 births (1984–88).



Community empowerment

Unlike many other Healthy Start programs, the Philadelphia consortium did not base its Initiative on a case management model. Instead, services are decentralized; Healthy Start supports 28 programs, which require almost 50 contracts. Fisher sees this arrangement as "an awesome responsibility, but then again, it is a wonderful opportunity." Before establishing services, the team asked the community to identify its needs. Work groups were formed to identify needs and propose solutions. This input helped the team plan the community-based services offered through Healthy Start. The coordinated approach of the Philadelphia team is best exemplified by the African proverb:

"It takes a village to raise a child."

To assure community involvement, the consortium strategically placed three community development specialists in the community. They talk with residents and gain their trust through methods such as open forums and presentations. These strategies facilitate this "client-driven" model of Healthy Start.

Use community development specialists from the community to promote linkages with the Healthy Start Initiative.

Linkages

The Healthy Start team found that there was a sense of competition among providers in the Healthy Start service areas—an "astounding" idea, Levi noted, in an underserved area. Linkages among providers help to alleviate this sense of competition by demonstrating that all are dealing with the same issues and can learn from one another.

© Establish linkages among providers so that they learn about common concerns and overcome fears of losing a client population.

Because a variety of agencies would be working with Healthy Start programs, it was important to form linkages and partnerships between institutional and community-based providers in order for all partners to be able to





work together as a group. Service providers in the community include not only clinics and social service agencies, but also community development agencies, churches, block captains, and others.

When forming linkages between institutional and communitybased providers, look beyond providers of health services; target other community-based organizations such as churches and community development agencies.

Many goals have been set for the Healthy Start Initiative, and each is represented in a work group. These groups meet regularly to discuss ways of improving Healthy Start services. The linkages work group looks for ways to develop more comprehensive and coordinated services and build the capacity of community-based and institutional providers.

• Build provider capacity to achieve the goal of establishing comprehensive services.

Early meetings of the linkages work group were held in various parts of the project area, to make it easier for participants to attend.

• Vary the settings of meetings and ensure that community members are not intimidated by the meeting location.

The work group began by facilitating linkages through workshops and referrals, but members soon wanted to expand their efforts. To do so, they planned a resource fair, which was held during the summer in the parking lot of a shopping center. Usually, at resource fairs, information is given to clients. However, this fair was different because it was directed toward providers as well. At this meeting, providers could meet face-to-face and share ideas and resources. This kind of meeting—which encouraged the development of relationships among providers—is crucial for successful collaborative efforts. While this meeting was important, it reminded the consortium of the need to move beyond networking into collaboration. Too often, people perceive competition, when, in reality, many opportunities for collaboration exist.

© Encourage providers to move beyond networking to take risks and share resources to achieve a common goal.

The Philadelphia team employs a variety of strategies to ensure the development of successful linkages.

One strategy was orientation and training. All Healthy Start providers must complete a two-day orientation. More than 150 Philadelphia providers attended the first orientation, where they discussed common issues and concerns and used each other's expertise to solve common problems. The provider network established by Healthy Start allows providers at all levels—including social workers, nurse midwives, nurse practitioners, case managers, and outreach workers—to continue talking about common issues.

© Sponsor orientation sessions on Healthy Start and support networking to encourage collaboration and linkages among providers.

All outreach teams and lay visitors attend the same type of training sessions so that they can meet each other, learn about mutual issues, and discuss



what they can do as a group. While this training is important, community development specialists called attention to the need to train all staff about Healthy Start. Consortium members and some other staff were aware of Healthy Start programs, but others—for example, some receptionists—had received no training on the goals or activities of the Initiative. In particular, it is important for staff working directly with clients to be informed about Healthy Start. Now, all staff members participate in an orientation so that each participant can share "the Healthy Start dream," noted Fisher.

• Train all personnel involved with Healthy Start about the yoals and activities of the Initiative.

Paperwork: One of the most difficult tasks for the Healthy Start teams in establishing linkages was completing the necessary paperwork. A linkage agreement confirmed that agencies knew what complementary services were offered by other agencies. However, the consortia soon realized that these agreements were "only a piece of paper," according to Levi, and not a communication agreement. Activities supported by Healthy Start—such as provider networks, collaborative meetings, consortia meetings, and work group meetings—allow members to establish meaningful linkages.

• Nurture communication and meaningful linkages among health providers. Even though extensive parerwork may be needed to establish these linkages, the communication is essential.

Resource guide: Another strategy for improving linkages was to publish an expanded resource guide listing all maternal and child health agencies in Philadelphia, including those outside the Healthy Start service area. The guide enables providers to refer clients and create linkages with other providers.





BOSTON PROJECT

Presenters: Amina Ali and Alonzo Plough

Although some of the world's most renowned medical institutions are located in Boston, some sections of the city have a high infant mortality rate. The Boston Healthy Start Initiative, which is managed Ly the city of Boston, aims to reduce this rate by changing behavior, attitudes, and the way health care is delivered to at-risk groups. First, the Initiative seeks to empower individuals, families, and communities by involving residents in the consortium; by increasing their awareness of the problem (and of available services); and by including nontraditional providers—particularly small, community-based organizations—in the project. Second, the Initiative will increase access to needed care and encourage the use of available services by establishing case management and home visiting programs and supporting health and ancillary services at health centers. A third goal is to build systems and program linkages through collaborative efforts with public and private groups. One program highlight is the Initiative's effort, in conjunction with the school system and health care providers, to establish case management and health and social services to pregnant and parenting teens in four Boston high schools. Through this program, and many others, the Initiative seeks to halve the area's infant mortality rate of 17.1 deaths per 1.000 births (1984-88).

Linkage, access, empowerment

The model guiding the Boston Healthy Start Initiative is "linkage, access, empowerment." Boston's Healthy Start consortium believes that it is important to identify gaps in resources for the community, and establish contracts with community groups to address those gaps. The team bases its strategy on the belief that decentralized grants will flow more quickly to the community.

Ali stressed the importance of understanding that organizations that respond quickly to requests for proposals (RFPs) are usually those best positioned to do so (i.e., they have grant writers on staff). The Boston consortium wanted to empower the community by decentralizing grant awards, giving them to nontraditional agencies and those in greatest need. When only well-established groups responded to the first RFPs, the consortium recognized that it needed to provide assistance to nontraditional groups to help them pursue the grants. During the second round of RFPs, the consortium actively recruited the involvement of other groups such as churches and social clubs, thus gaining the involvement of nontraditional providers.

Provide assistance to community-based organizations attempting to respond to RFPs. Sending out RFPs without aiding small, nontraditional, community-based groups will discourage their involvement, and result in the submission of proposals only from more established organizations.

Special problems persist after smaller, community-based organizations are awarded contracts. Ali noted that the cost reimbursement process does not work well for organizations with cash flow problems. It is easier for a large company than for a smaller company to "hold" bills for 90 days—the time needed for reimbursement. For this reason, the implementation process was difficult for the Boston consortium.

Be prepared to adjust reimbursement systems when working with nontraditional providers.

Although "we think money is empowering," according to Ali, this is not necessarily true. If too many stipulations accompany the funds, people will be unable to work as flexibly as they had before (i.e., as volunteers). Funds decentralized to the community may be difficult to manage.



• Empower communities through funding, but do not expect that these funds will guarantee success.

Management and governance

Lessons on managing the project were important for the Boston team. One early experience stressed the importance of monitoring the work of the project director early in the life of the project. The Boston team experienced some chaos when its first project director left, and learned the following lesson:

• Recruit and hire permanent staff quickly.

The city's Healthy Start Initiative was community-driven "from the time the RFP came out," and this mission characterizes the Boston model. At no time did the city health department believe that it was going to define the process of planning and implementing Healthy Start. A major goal was to decentralize the Healthy Start Initiative and the federal grant award as much as possible. Through the early volatile period, the consortium learned the importance of defining "up front" the formal power relationships.

• Pay attention to critical governance issues early and establish equitable partnerships.

As the government partner in the Healthy Start Initiative, Ali admitted that she represented the partner in the Boston consortium with "the most to learn" and the group "most challenged" by the Healthy Start mandate for empowerment. To be successful, the government partner would need to "reinvent practices." It is important for government entities to learn to relinquish power and enable other groups to take charge when appropriate. The process is difficult—and origoing. There is always a creative, dynamic tension as partners learn how to deal with changing power relationships.

© Encourage government agencies to give power to the community. While difficult, this process is important and has a critical long-term impact on the project and the community.

Boston's consortium codified working relationships early. The Boston team wrote a memorandum of agreement between the grantee and the community. Although this is a formal legal document, it can be modified over



time and can help the community achieve equity and ownership of the project. The consortium can return to these principles whenever there is uncertainty. Ali stressed the need to document changes in these relationships, in detail, on paper. Whenever difficulties arise, this documentation helps project staff honor such changes.

• Codify working relationships so that future problems can be addressed by examining agreed-upon principles. Describe an equitable relationship between the community and the grantee on paper.

Boston's diverse community gave rise to an important governance lesson. Ali observed that "you can't get too detailed in your understanding about governance." Because the Boston consortium is composed of community residents who are culturally and linguistically diverse, it is necessary to have a representative governing body. The consortium's executive committee is composed largely of residents, and mandates require that its ethnic composition reflect that of the community. "You don't get to empowerment through rhetoric," emphasized Ali; instead, real actions must be taken.

• Establish governing bodies that reflect the ethnic composition of the community.

Combining traditional and nontraditional systems may be difficult, and the groups may encounter problems when working together. Community members, although they may not be "credentialed," may bring special skills to the consortium—skills that enable them to make valuable contributions to the effort to bring together different systems.

Evaluation

In addition to documenting all processes, Ali noted that frequent evaluations are important. "We feel we must show what works" and what does not, and be held accountable to the consortium. Prior to implementation of Healthy Start, the African American infant mortality rate had already declined by 50 percent. If this change had not been documented, later evaluations of the outcomes would have been incorrect.

• Pay attention to evaluation, a critical component of Healthy Start.



PITTSBURGH PROJECT

Presenters: Carol Synkewecz and Reverend Robert Dye

The Pittsburgh Healthy Start Initiative provides health services and also addresses the social and economic problems of project area residents. Community-based programs and services focus on reinforcing traditional family values, promoting individual responsibility, and looking toward the community's strengths for developing solutions to the infant mortality problem. Strategies include expansion and coordination of health and social services (such as perinatal care, family planning, substance abuse treatment, nutrition services, and literacy training); a multimedia outreach effort, which includes weekly radio talk shows and a telephone Help Line; and outreach/case management teams consisting of community health nurses. social workers, and outreach workers. Local consortia identify special community needs for the Initiative. The program is managed by Healthy Start, Inc., a nonprofit organization which works in close collaboration with the grantee agency, the Allegheny County Health Department. Innovative approaches include Bank Days, in which prenatal registration is available at local banks on common deposit days; Bright Start, a program that provides free laundromat services to pregnant women who enroll in the program; screening in the county jail for HIV and sexually transmitted diseases; and certification classes for residents in infant cardiopulmonary resuscitation and in HIV education. It is hoped that these intensive efforts will reduce by half the area's infant mortality rate of 20.2 deaths per 1,000 live births (1984-88).

Management and governance

Synkewecz noted that the Pittsburgh Healthy Start Initiative is both "evolutionary and revolutionary" and that the team is still learning. The Pittsburgh consurtium designed the project as a grassroots effort from the beginning, and specifically looked for ways to involve the community throughout the process. By establishing a nonprofit organization to operate Healthy Start, the consortium embarked upon a "different way of doing things."

• Encourage grassroots participation and involve the community early in the process of setting up programs.

Pittsburgh's consortium established a nonmedical model for its Initiative, so that the team could bring about change within the health department, hospitals, and human service agencies.

Community empowerment

If the program is community-driven, noted Dye, there must be "equality of power sharing." In Pittsburgh, the nonprofit organization's board of directors is composed of community members who have the power to hire the executive director independent from the authority of the health department. Consensus building is stressed, and each region contributes to the decisions. Outreach workers are hired only after interviews with representatives from the community. Power sharing involves risk-taking and trust, but is crucial for the success of the program.

• Stress equality of power sharing; there can be no empowerment without ownership.

The health department made a "bold, visionary" decision in empowering a nonprofit organization to lead Healthy Start. However, this action forced all participants to share "collective responsibility" for Healthy Start. If the program succeeds, all succeed; if it fails, all fail. The community must be given the freedom to stumble and make mistakes. Some were afraid to share the



power for decisions such as setting salaries, hiring staffs, and implementing policies, but collective responsibility could be achieved only through power sharing among partners.

• Learn the meaning of sharing power through participatory leadership, consensus building, and collective responsibility.

Anticipate a "wild ride," with all of the ups and downs as the project develops an integrated system, cautioned Dye. All involved with Healthy Start teams need to learn how to share power, take risks, and expect some pain.

• Anticipate both agony and joy with the process of consensus building.



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Program initiatives

Prior to the beginning of Healthy Start, on-site coordination of maternal and child services had not been established between WIC services and hospitals. Programs could not be co-located (e.g., in hospitals) until Healthy Start provided the stimulus to change how services were delivered. After one hospital agreed to co-location of WIC services, the other participating hospitals also wanted co-location. Through Healthy Start, WIC and prenatal care appointments were combined. As a result, the time spent by patients waiting for appointments decreased; extra trips to WIC clinics were eliminated; and there were more incentives for patients to keep appointments. In addition, locating WIC/nutrition programs at community health centers with prenatal care minimizes travel and reduces the number of appointments so that more counseling, education, and group programs can take place. In the first two months of the program, 132 women were enrolled. This efficient use of resources was not only effective, but also well received.

- Integrate and co-locate Healthy Start and WIC/nutrition services to maximize participation and use resources effectively.
- Improve the timeliness of early enrollment in prenatal care and food distribution.

Community health centers work together with the county health department to incorporate well-child services with primary care services, thereby enhancing a whole-family approach to care. Through these efforts, Healthy Start has stimulated hopes to create a combined community health and public health system in which resources are maximized, staff share learning and training, and families receive comprehensive care.

- Help health department personnel to understand that "they cannot do it all alone."
- Integrate services to reduce costs and expand resources.

The Healthy Start team has also improved health services for incarcerated women. Historically, few programs have been available for this group, but Healthy Start is beginning to serve approximately 15–20 incarcerated pregnant women as well as other incarcerated women. Nurse-midwives are providing



obstetric/gynecological services and health education to this group. Because of Healthy Start's leadership and the cooperative spirit fostered by the Initiative, this vulnerable population will receive the services they need.

- Develop programs addressing the needs of incarcerated women.
- Facilitate and deliver needed services, such as education and family support services, to incarcerated women, and link them with Healthy Start services after their release.



QUESTION AND ANSWER PERIOD

Community residents at the national grantee meeting

An audience member emphasized that people served by Healthy Start grants should attend grantee meetings so that Healthy Start leaders can obtain input from consumers.

Empowerment and financial support

Another member of the audience asked the panel what empowerment really means, especially after Healthy Start funding ends. One panelist suggested that different project teams talk with each other and share ideas and suggestions about empowerment.

• Network with each other and share ideas about effective strategies for empowering Healthy Start communities as well as ideas about economic development.



THE HEALTHY STARY INITIATIVE



BIRMINGHAM PROJECT

Presenter: Dorothy Patterson

The Healthy Start Initiative in this inner-city region of Birmingham seeks to reduce infant mortality in the project area by providing a variety of key services. Operated by the Jefferson County Health Department, the Initiative provides a mix of services at 12 sites, with activities designed specifically for the needs of each of the 12 communities. Common efforts include smoking cessation programs: case managed maternity care: substance abuse and spousal abuse services; health and parenting education; nutrition counseling; and assistance in completing applications for WIC, food stamps, and Medicaid. Family planning services and preconceptional risk assessment, counseling, and care have been expanded to help clients postpone and/or improve outcomes of high-risk pregnancies. To make it easier for clients to access services, child care and transportation are provided. Home visiting and outreach are important strategies as well. In these efforts, as in the design and implementation of the entire project, the Initiative has relied on input from a consortium which includes representatives from the public sector (the state public health and Medicaid agencies and county and city agencies), the private sector (including United Way), and academia (University of Alabama-Birmingham). All participants are working toward a common goal of reducing by 50 percent the project area's infant mortality rate of 18.4 deaths per 1,000 live births (1984-88).

Community empowerment

In its planning phase, the team sponsored community meetings, conducted telephone surveys, and held focus groups. In creating the consortium, project staff did all that was required to obtain the grant award. "Our hearts were in the right place," explained Patterson, but "what we did not account for was the interplay of culture and class differences" and the impact these factors would have on the operation and success of the program. The Birmingham consortium believes that there must be respect for cultural differences, especially in customs, history, values, beliefs, and feelings. From this experience, the team learned this lesson:

Be sensitive to culture and class differences. Consider cultural aspects when implementing programs in minority communities.

At the beginning of the project period, the Department of Health identified leaders in the community, but never asked the community: Who are your leaders? "Our attitude reflected that we did not take into account the intergroup differences and the clients we were called to serve." Leaders chosen to participate with Healthy Start did not represent class and age differences in the target populations. Thus, the consortium learned the importance of this lesson:

• Ask the community who their leaders are when looking for community representatives for Healthy Start consortia.

When planning Healthy Start activities, recounted Patterson, "we believed we knew better" than community representatives. However, once the planning stage was over, the community "called our hands," telling project staff that "you didn't ask us what our needs are. What you see as our needs are not what we know are our needs." The community saw poverty and violence as key factors leading to high infant mortality rates. The community told the Healthy Start team that "when these issues are addressed, our babies dying will no longer be the issue." Community members were concerned with drive-by shootings, a lack of jobs for young men, adolescent pregnancy, and drugs. Safety, education, employment, and substance recovery were important to the community—but community members believed that project staff "had discounted them," in a project that was supposed to be "a cooperative



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relationship with the community." Community members did not trust project staff; staff had intended to be sensitive, but the outcome was viewed as insensitive.

Ask the community to identify its problems, concerns, and needs. Do not assume that the priorities of project leaders are necessarily the priorities of community members.

In addition to listening to the community about its priorities, the team needed to listen to fears voiced by community residents. Birmingham has the largest medical center in the Southeast, a center with many research components. Recalling the study conducted in Tuskegee, Alabama, community members wanted to know whether they would be researched again. "Is this another test?" they asked. If so, they did not want to participate in the Initiative. In addition, they cautioned: "If you are bringing the money, make sure it gets to us, that it doesn't go to the top and we never see it." It was important for the team to recognize this suspicion.

• Be aware of historical reasons for community suspicion of health initiatives.

Management and governance

In reaction to the outcry within the community, and "our desire not to have our behavior viewed as carrying on business as usual, staff gave large parts of the project over to the community. Although people from the community were sensitive to residents' needs, they lacked management expertise. Staff did not take into account the fact that it was the top managers in the health department who had the necessary management expertise. These top program management positions are "usually held mostly by white men," and the community believed that these managers were not sensitive to community needs. It became apparent that each group needed the other's strengths and that the programs would be most successful with linkages between traditional and nontraditional systems.

"Share the vision, empower the community, build a partnership, and handle conflict constructively." The team asked itself the following questions: To what extent do the unintended consequences of policies, practices, and procedures function to the disadvantage of Healthy Start? To what extent do rules and regulations fuel conflicts? For example, outreach workers were recruited by people from the community, not through the personnel system, so the workers were more loyal to community leaders than to the health department. The Healthy Start team wanted to bring community members into the system and thus saw the need for procedural changes to make community members feel comfortable and to examine policies dealing with race, class, and age differences.

 Examine policies, practices, and procedures for racial, gender, and age bias.

Lessons of hope

Throughout this meeting, speakers have stressed common themes that affect all Healthy Start consortia and the planning and implementation of the national Healthy Start Initiative. The Birmingham project faces many of the same issues and problems. The project has had to accept challenges and move forward, bringing diverse and often conflicting groups together to reduce infant mortality.

Patterson emphasized that the team is hopeful for the future. Understanding the importance of personal attitudes, interpersonal behaviors, institutional rules, and cultural preferences will help the Initiative succeed. In general, Healthy Start sites must recognize that there will be successes beyond the life of the grant. Patterson believes that the consortia should "stop beating ourselves up because we didn't get it right the first time," in the prescribed time frame. Issues need to be addressed over the long term, and the team believes that Healthy Start, which brings together community collaboration, is the vehicle to make the necessary changes.



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OAKLAND PROJECT

Presenter: Mildred Thompson

Known as the "Oakland Flatland," the project area included in this Healthy Start Initiative is an inner-city region. The Alameda County Health Department oversees this project. Two major approaches characterize this Initiative: establishment of a Family Life Resource Center in each of the three target areas, and expansion of clinical services through an improved and integrated service delivery system. The family life resource centers offer holistic community health and development activities, including community revitalization (such as developing neighborhood associations); economic development; health promotion and medical services, including screening for sexually transmitted diseases, family planning services, nutritional counseling, and substance abuse prevention workshops; family empowerment activities; and special programs for adolescents. The capacity of the system to provide obstetric, pediatric, and mental health care will be expanded with support from Healthy Start. The Initiative promotes a "one-stop shopping" concept and the development of a shared management information system. By working in close collaboration with the community and providing the services it needs, the Initiative aims to reduce by 50 percent the area's baseline infant mortality rate of 18.0 deaths per 1,000 live births (1984-88).



Management and governance

The Oakland team works with community-based organizations, but since the county health department is the grantee, the project remains a part of the county bureaucracy. Program staff must contend with levels of bureaucracy, yet are still pleased with the advantages of being within the health department. Creating a balance between the needs of Healthy Start and county requirements is an engoing issue for the Oakland team.

Debate within Healthy Start has focused on establishing the structure of the Initiative. In the planning phase, the team decided that only community-based organizations—not the county—would provide direct services. The team was determined not to create a new service delivery system, but to use Healthy Start funds to make existing systems work. When implementing these plans, the team also wanted to ensure that the county was not directing the effort, but that community-based organizations were overseeing program initiatives. Thus, the team must find a balance when seeking to meet the needs of the county, the community-based organizations, and the federal government, while attempting to "still be true to the planning commitment" made in collaboration with the community.

Oakland's efforts are focused around family life resource centers. These sites provide one-stop shopping, places where infant mortality is addressed through a range of community-based services. The primary focus is on providing social, rather than medical, services. These facilities are designed to offer "everything a family needs"—including neighborhood revitalization; neighborhood watches; tenant associations; prenatal and parenting classes; GED classes and coursework in English as a second language; and cultural activities. Clinical services are provided, but they are funded separately.

When establishing these centers, program staff took a "hands-off" approach. Healthy Start staff created the structure of the RFP and provided funds, but then allowed the community to do the work. Because the resource centers needed to sponsor many activities, it was impossible for one agency to provide all of the needed services. Thus, it took time for the community-based organizations to develop subcontracts, work with program staff to have plans approved, and implement initiatives. While the plan called for operational centers within six months, the resources centers were not operating effectively until the second year of the grant.



Set realistic time frames. Oakland's consortium found that it was ambitious to expect that the program could become operational in six months.

Collaboration is critical to the project. but it takes time and hard work to develop working collaborative relationships. Program staff want to allow community-based organizations the freedom to implement services, but also want to be seen as partners. For example, the county must be concerned with grant requirements—such as data collection—which are not viewed as a priority by the community. A balance must be struck between the desire to allow community-based organizations to direct the provision of services and the need to obtain the data required by the grantee.

Recognize that collaboration takes time and hard work, and that it can be difficult to turn over services to the community if its members do not understand global issues, especially the need for data collection.

Staff are especially concerned about the accountability of funds. Although the grantee has turned over responsibility for Healthy Start programs to community organizations, it is still responsible for appropriately managing the funds. "We are accountable for those tax dollars, and that is difficult and scary," noted Thompson. However, there are long-term rewards.

Collaboration

The Oakland consortium has learned some important lessons about building a consortium successfully. First, the team learned the importance of devoting time to planning. Questions that should be asked include: Who is necessary to be a part of this partnership? What is needed in order to do this successfully? "The answer," stressed Thompson, "might not even be you!" Instead, it may mean that an organization must realize that another group is a better choice, and offer to help that group develop plans. "That's a level of sharing that we haven't gotten to yet," admitted Thompson. Establishing these collaborative partnerships requires time spent planning before any action is taken.

- Involve all partners very early in the process. Involvement must begin before collaboration, so that time can be spent planning.
- Choose collaborative partners carefully. Who should be involved? What is needed from partners?

Thompson also emphasized the importance of recognizing the special abilities of each of the consortium partners. Many people "have good hearts, but they don't know how to really run an agency." An organization may be very good at outreach, for example, but if it lacks administrative experience, then administrative responsibility for the project should not be in its charter. "We're talking about honesty," said Thompson, who stressed that all partners must agree on the strengths and challenges of each group, so that they can establish better working relationships. Only by continuing to work together can these agencies form the "bond" needed for working collaboratively on programs. While forming partnerships, all members should be careful to obtain signed agreements before entering into a contractual arrangement. These agreements may be critical at a later date if partners question the original proposal.

- Recognize the strengths and challenges of the partners in the group.
- Stress honesty: agencies should recognize their strengths and weaknesses.
- Obtain signed agreements between partners. Later, these agreements may help to clarify issues of uncertainty.

Thompson urged consortia to move "to a level beyond collaboration."

Guiding principles

"I've had to practice my own internal restraint," reflected Thompson, as she shared one of her most valuable lessons:

• Remember the "three P's": practice. tience, and prayer. These are three important guiding forces. "Perfection will take awhile!"





PEE DEE REGION PROJECT

Presenter: Roger Poston

In the northeast corner of South Carolina, six rural counties-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 (e.g., 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 baseline infant mortality rate of 16.1 deaths per 1,000 live births (1984--88). The goal is to reduce this rate by half by 1996.



Collaboration

Poston recalled that, when the project was being discussed, everyone promised to collaborate and to work toward common goals. When the time came to distribute money, however, the "sun rose on a different day!" People were still "around the table," but it was a different environment. Thus, the project had to work through some early problems.

Be prepared for increased tension when grant monies are being distributed. Relationships among members of a collaborative group may become more strained when dissemination of money is involved.

No agency can assume the burden alone, according to Poston, so the Healthy Start team in Pee Dee has encouraged all groups to meet and work collaboratively and listen to the consumers of services. Poston acknowledged the important role of Lillie Fox, a conference attendee and consumer from Pee Dee who made vital contributions to the project.

• Recognize the important contributions of consumers, and show-case these contributions whenever possible.

Collaborative work can be difficult, and can take longer than expected. This is a demonstration project, so consortia must work at an accelerated pace to accomplish the Initiative.

Outreach

Pee Dee is a rural region in which northern and southern areas are separated by more than 100 miles. The large geographic area encompassed by the project exacerbated some problems.

• Choose the geographic target area for a demonstration site carefully; attempting to cover a large geographic area can be problematic.



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The Initiative addresses the special needs of this rural area through its ROADS teams. This program provides care to women who cannot access site-based services. When the project requested proposals from providers to create and manage the ROADS teams, it encouraged competition. However, the providers (as the dominant players in these rural counties) were resistant to going through the effort to develop competitive proposals. Only one RFP from each county was received, and the consortium deemed five of the six proposals nonresponsive. When the request was sent again, technical assistance was offered to help groups write responsive proposals. From this experience, the consortium learned that it needed to involve community members more actively so that they knew what to expect from the Healthy Start Initiative.

- Involve the community actively from the beginning, before RFPs are disseminated.
- Offer technical assistance to all agencies and organizations planning to respond to RFPs.

The consortium has worked through early problems, and ROADS vans are operating in all six counties.

Program initiatives

Pee Dee Healthy Start has undertaken a number of projects in addition to the ROADS teams. These initiatives include recruiting providers, sponsoring child care services and transportation, establishing Teen Life Centers, supporting school-based clinics, and working with churches.

Recruitment and retention of providers: All counties in the rural Pee Dee region are classified as medically underserved. Three of the six are doubly underserved. Generally, providers prefer urban settings. The consortium believed that a collaborative effort involving hospitals, health departments, and community health centers in all six counties was needed to recruit and retain health care providers.

• Use creative, collaborative campaigns to recruit and retain health care providers in underserved areas.



Child care: Lack of child care prevented some women in the Pee Dee region from visiting clinics. The consortium established drop-in child care, currently available at two community health centers. Other child care options are being explored.

• Offer child care to remove an important barrier to accessing services.

Transportation: There is a lack of public transportation in this rural area, and most residents do not have access to cars; 25 percent do not have telephones. The consortium is working with the community to assess both traditional and nontraditional transportation alternatives and to develop creative solutions to the problem.

Teen Life Centers: The Pee Dee consortium disseminated RFPs for Teen Life Centers in all six counties. Friendly competition among respondents was encouraged, and the response w.s better than for the ROADS project. Each Teen Life Center links adolescents with all available services and has an advisory committee which includes teen members. Centers provide health education, career planning, and recreation. Recognizing the importance of early health education, the team will also take programs to children before they enter the high-risk adolescent years.

Interfaith initiative: In the South, "churches play a major role in values and life direction," commented Poston. As part of the interfaith initiative, churches in each of the six Pee Dee counties submitted proposals with a variety of ideas about how they could have an impact on the problem of infant mortality. Some offered to provide maternity and infant clothes to Healthy Start clients; others wanted to sponsor workshops for adolescents featuring health education programs; still others offered to provide drop-off child care for women seeking services, or transportation to site-based clinics.

• Seek to involve local churches—they can be valuable partners.

School-based clinics: "I think all children in America are at risk: black, white, rich, poor—it doesn't make a difference," stated Poston. Providing care through school-based clinics or nurses is an important strategy. There are questions about expanding the school's role, and concerns that



schools are not equipped to provide traditional health care. But through collaboration and flexibility, important contributions can be made.

Guiding principles

The lessons learned by the Pee Dee consortia can be summarized in six key principles.

Remember the "six C's":

- 1. Commitment (from individuals, agencies, and organizations)
- 2. Cooperation (providers cannot assume "business as usual")
- 3. Collaboration (work together for greater impact)
- 4. Community (there must be community ownership of the project)
- 5. Communication (across all levels)
- 6. Creativity (new approaches are needed to solve long-standing problems)



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THE HEALTHY STARY INTLATIVE



NORTHERN PLAINS PROJECT

Presenters: Donna Vandall and James Hudson

Spread out over four states-Iowa, Nebraska, and North and South Dakota-the Northern Plains Healthy Start project area is composed of 19 Indian communities located primarily on reservations. This Healthy Start Initiative focuses exclusively on Native Americans, and is run by tribal leaders through the Aberdeen Area Tribal Chairmen's Health Board. Through this Initiative, the tribal leaders have made a commitment to helping their people reestablish strong, healthy families and achieving a 50 percent reduction in the high rate of infant mortality among Native American babies in this region (an average of 18.7 deaths per 1.000 live births during 1984-88). Overlap in geographical boundaries, a transient population, and the vast distances separating project sites all create difficulties in directing the project and providing services. The goal of the project is not only to reduce infant mortality, but also to address a wide range of issues for families. Alcohol consumption during pregnancy and physical violence toward women are important issues for this population. The Healthy Start team believes that direct community involvement in planning and implementing the project will encourage participation and promote its success. The Initiative seeks to ensure that a high-quality system of locally accessible primary care and transportation to health care is readily available for all pregnant women and infants. Through their joint efforts, project staff and community leaders seek to promote infant health and stress its importance to the whole community.

Healthy Start for Native Americans

Since the Northern Plains project is so different from the other 14 Healthy Start sites, Vandall shared some background information on its unique characteristics. First, the 17 tribal governments in the project area (each of which governs a reservation) play a critical role. Each tribal government has a representative on the Aberdeen Area Tribal Chairmen's Health Board, which is the grantee agency for this Initiative; these 17 representatives are joined on the board by one representative from the urban community in the project area, Rapid City, and one representative from a rural community, the Trenton Indian Service Area. Tribal governments are recognized as governing bodies under treaties with the U.S. government negotiated through concessions of land, which guaranteed health, education, and welfare to the populations. Each tribal government addresses economic development, social services, and law enforcement, and each has access to a U.S. senator. These tribal governments have a very important influence on the lives of the Native Americans. In addition to the tribal governments, there are two health organizations, 19 site coordinators, and the Tribal Chairmen's Health Board. The Bureau of Indian Affairs and the Indian Health Service are the primary service agencies acting in the area; there are no foundations or companies with thousands of employees in these regions.

The area covered by the reservations encompasses some of the "poorest, meanest areas" of the United States. The Native American culture is still alive in these regions. Even though many of the residents of the project area have adapted to modern changes, they have also maintained and passed on much of their ancestral history and philosophy to younger generations. At the center of the team's philosophy is the belief that "like the circle, there is entire wholeness and connectedness in the universe."

Hudson noted that attending consortium meetings is difficult because of the great distances that separate participants. Much of the first year of the project was spent traveling (made more difficult by harsh winters). Traveling long distances over the varying terrain of the four states continues to pose challenges for this Healthy Start team.

Of the 12 Indian Health Service areas, Aberdeen, South Dakota, has the highest rates of infant mortality, cancer in women, unintentional injuries, and alcoholism. Even though many of these problems exist, Vandall described how the Northern Plains team has learned to be proud of "accomplishing many great things."



Share information about program accomplishments, especially when unique qualities prove critical in the operation of a program.

Building consortia

Since all of the 17 tribal governments function as true governments with judicial, executive, and legislative branches, many people are involved in the Healthy Start consortium. Medicaid and maternal and child health (MCH) representatives, consumers, and elders participate. Elders from the tribal governments provide the Northern Plains team with insight concerning those who should be included in the consortium. Initially, the consortium included about 200 persons, a large group that proved difficult to organize. During the project's early stages, membership and political structures were in flux. These early experiences taught the Northern Plains team the following lesson:

Recognize that consortium building is a dynamic process, and that early consortia may change considerably.

The number of participants involved in the Northern Plains consortium later decreased to a more manageable size (approximately 70 persons). Even with this reduction, Hudson still stressed the following principle:

• Involve consumers, elders, and community members in the consortium.

Management and governance

Important lessons learned for this Initiative include those related to management information systems. The team found it difficult to collect the required data (20 pages) from clients; instead, the team developed a mechanism to collect data as services were provided. Even so, the Northern Plains team may "never have a complete data set." This experience reinforced an important lesson:



Tailor data tools to the specific needs and situation of a community.

The Northern Plains team developed a computer system that records events as they occur and tracks patients as data are collected. For example, if a client's blood pressure rises, the system tracks the change from a normal to a high-risk category. The consortium has also established a local area network which enables members of each site to communicate with each other and with the other sites. This system enhances communication, an especially important consideration given the great distances between sites.

Use technology such as electronic mail to enhance communication, especially when faced with geographic barriers.

Hudson also described the positive outcomes of designing a community-specific data tool. The Northern Plains team created an innovative model by combining Healthy Start philosophies and functions with MCH standards and guidelines. The consortium hopes this system will become a "driving force" that will be included in MCH plans and will allow "Healthy Start to stay with us." This new Healthy Start/MCH model has the potential to be adopted, used, and eventually funded by the Indian Health Service. Hudson stressed that the model is effectively serving the needs of community members, the consortium, and project staff. By establishing protocols for the actions of the Healthy Start consortium and participants, the team has gained credibility for the Healthy Start program.

• Establish systems that will help perpetuate the Healthy Start philosophy, even after the program ends.

QUESTION AND ANSWER PERIOD

Sustainability of Healthy Start Initiatives

A member of the audience asked the Northern Plains Project representatives, Donna Vandall and James Hudson, how they hoped to sustain Healthy Start activities—particularly socioeconomic components—after federal funding ends. Hudson explained that protocols for third party reimbursement,



which were developed and fostered with the tribal governments through the Healthy Start/MCH model, can be sustained without Healthy Start funding. The Healthy Start philosophy can be perpetuated through the tribal governments, which can seek additional funding through the Indian Health Service and the U.S. Congress. Finally, the way in which the community looks at the "whole picture" will help to perpetuate Healthy Start, which is founded on similar principles.

Vandall explained that, on a reservation, "severe unemployment" may mean an unemployment rate of 87 percent. Therefore, members of the consortium are continually thinking about these issues and seeking innovative ways to address their problems.







NEW YORK CITY PROJECT

Presenter: Cynthia Pinn

The goal of the New York City Healthy Start Initiative is to create and sustain a new collaborative mechanism through which political leaders, health and social service agencies, private providers. community-based organizations, religious groups, foundations, educational institutions, businesses, and individual consumers can work together to address infant mortality. Efforts are directed by the grantee. Medical and Health Research Association of New York. Inc., and carried out by lead agencies in the three inner-city service areas. United by this project, the service areas are unique communities that have designed activities specifically to meet the needs of their populations. The Bedford service area has established a centrally located, multiservice center. where staff perform initial health and social assessments of clients and refer them to case managers. The Central Harlem area works with five multiservice centers, using existing health care and social service agency sites as bases. The Mott Haven area takes a decentralized approach, using Healthy Start resources to enhance staff of key providers and intensify outreach to the community. The Initiative has conducted various types of training, such as sponsoring a basic course in maternal and child health for staff of community-based organizations and training registered nurses as obstetrics/gynecology nurse practitioners. These efforts, and many others, should help to reduce by 50 percent the area's infant mortality rate of 19.4 deaths per 1,000 live births (1984-88).

Mission

The Healthy Start/New York City program employs a comprehensive approach to reducing infant mortality in its target communities. Early in the development of the program—even prior to developing the needs assessment—the team acknowledged that the medical model alone was not sufficient. To reduce infant mortality, other important indicators such as socioeconomic status, education, and housing must also be addressed. The entire team learned these lessons:

- © Recognize and address nonmedical causes of infant mortality. Work toward improving and developing a coordinated and integrated system of care for women and their families.
- Build on existing community-based resources, and involve the community in planning and implementation.

Management and governance

The three communities in the New York City Healthy Start project area are full partners—and a major force—in this effort. The grantee is a private, nonprofit organization which is working closely with the three communities, the state, and the city to coordinate efforts. The community was active in the planning phase, but sustaining this participation is challenging. The Healthy Start team supports community participation in a variety of ways.

• Allot funds to support community participation; for example, fund activities such as transportation and child care. Supporting these types of activities is one way to involve the community in the consortium.

The community chose an integrated services approach for the Healthy Start project. Each service area offers a range of services, but tailors them to the area's specific needs. In Brooklyn, there is a central intake and referral unit and n any services are offered in the same complex. The Harlem team contracted with community-based organizations, while the team in the Bronx outstationed community health workers in a number of different locations.



• Meet specific community needs by allowing flexibility among different service areas within the same project area; always acknowledge that each community is unique.

Program initiatives

The New York team encourages community ownership of the program through some nontraditional initiatives. The consortium has faced challenges and achieved success with approaches including a farmers' market, a housing initiative, an internship program, a newsletter, and increased linkages among providers.

Use nontraditional methods to address specific community needs.

Farmers' market: The community developed and embraced the unique idea of holding a farmers' market, and the Healthy Start team provided technical assistance and funds to manage these special markets. The markets featured quality, affordable produce, and were well received and well attended. The U.S. Department of Agriculture permitted WIC coupons to be used at the market. Challenges included time constraints (markets were held only during the summer) and struggles to find adequate support staff for the program. This approach, however, yielded some direct accomplishments. Many WIC coupons were redeemed, and the Healthy Start team successfully provided detailed health education to many community residents. Finally, by offering quality services (and a petting zoo to entertain children and families), the consortium found a successful way of reaching the community.

- Sponsor farmers' markets coordinated with WIC services as a way of offering quality, affordable produce to the community.
- Seek collaborative ways to provide quality services and creative interaction with the community.

Housing: Through its housing project, the consortium sought to convert city-owned property into tenant-owned cooperatives. The team had to



deal with challenges such as ensuring community ownership of the project and encouraging cooperation among city agencies. Accomplishments included extensive community education and improved tenant organization skills. In describing these challenges and accomplishments. Pinn emphasized another lesson learned by the team:

Recognize that the challenges and accomplishments of a given project are often the very same thing. In the housing project, although community education and outreach were difficult to achieve, they were among the project's most tangible and positive outcomes. That which is often difficult to approach may offer a sense of positive achievement.

Newsletter: The Healthy Start team publishes a newsletter to share its experiences with all involved.

O Distribute newsletters to share information (and lessons learned) with all involved with Healthy Start.



Internship program: The internship program enabled 13 high school students to explore opportunities and build skills. The team faced unexpected challenges, however, when it had to deal with the interns' personal and social problems.

• When establishing an internship program, recognize that interns may require assistance with serious personal and social problems.

Challenges of running this program included issues such as coordinating training needs, managing time constraints, and dealing with the varied problems of the interns. Benefits included a 100 percent completion rate, since all participants finished the program. The high school students documented their summer experiences by writing a paper about themselves in the Healthy Start newsletter. In addition, support systems developed by the project staff and their willingness to invest time in others proved rewarding for all. Pinn stressed that, although the program was successful in its limited form, it should be extended beyond the summer. When describing the intern program, Pinn again underscored the New York formula for success:

• Consider both the challenges and accomplishments of a program to obtain lessons learned from the results

Linkages among providers: The New York consortium brings providers together so they can learn who they are as a group, and what they do. By initiating such "institutional activities," Healthy Start will leave behind an "enhanced community" at the end of the project's funding period.

Guiding principles

Pinn concluded with the lesson of the "three M's":

• Machinery (public policy and legislation) + Materials (public and private funds) + Manpower (Healthy Start community and providers) = Quality programs.



QUESTION AND ANSWER PERIOD

Provider sensitivity issues

An audience member asked about provider sensitivity training. Cynthia Pinn (New York City) responded that the New York City consortium has developed several programs, including one-on-one workshops, that are intended to improve provider sensitivity to cultural issues. These programs are especially important in service areas comprising many different populations, including Caribbeans in the Bronx, African Americans in Harlem, and Latinos/Latinas in Mott Haven.

Recognize the diversity of provider sensitivity issues, and involve all Healthy Start providers in programs to improve their sensitivity skills.



THE HEALTHY STARY INITIATIVE

WASHINGTON, DC, PROJECT

Presenter: Barbara Hatcher

The DC Healthy Start Initiative, operating through the Office of Maternal and Child Health in the District of Columbia's Department of Human Services, has undertaken a variety of activities aimed at reducing infant mortality in the two wards that comprise the project area. One goal is to develop the project area's perinatal system into a cohesive primary, secondary, and acute care service network, one that allows for collection of common data elements and elimination of access barriers by outstationing Medicaid eligibility workers. Case management is a core activity: public health nurses work in the community, and resource parents provide social and family support for pregnant women and families. Other efforts include augmenting existing community-based clinics so they can provide "one-stop shopping," and establishing two new comprehensive service centers. Nontraditional service sites are also used, such as a pediatric mobile clinic, Maternal Obstetrical Mobiles (MOM) vans, and school-based adolescent health clinics. Outreach to the community involves consumer and provider education to encourage support for project efforts, and "Healthy Start ambassadors" who provide outreach education and peer support. During the five-year project period, the Healthy Start team hopes to halve the infant mortality rate of 23.2 deaths per 1,000 live births (1984-88) for the target area in the nation's capital.



Program initiatives

The DC Healthy Start Initiative has learned many lessons as it has established services and educated the public about infant mortality and program services. Programs include public education, a hotline, MOM vans, resource parents, and support for male involvement.

The team has produced two brief videotapes to introduce and publicize the DC Initiative. In addition, a monthly cable program is produced in cooperation with the University of the District of Columbia.

Public education: It is important to "make health care a part of overall thinking" about issues.

© Conduct public health education in communities to connect local health providers to the community and to educate residents.

Hotline: A 24-hour hotline (1-800-MOM-BABY) is available to the community. Hatcher stressed the importance of having friendly, knowledgeable project staff answer the phones. Mothers who call the hotline and receive the information they are seeking may be willing to participate in other Healthy Start activities and to call the hotline again. The DC team learned the following lesson early in the program:

Develop and maintain a 24-hour hotline for moms, potential moms, friends, and family members. The DC team stressed the value of having a consistent and reliable community resource that is easy to remember.

MOM vans: The mobile obstetrical mobiles transport mothers to their appointments. These vans provide a needed service for pregnant and postpartum women and their infants who have no other transportation to health care services. Through this successful strategy, the team has been able to help mothers who abuse substances to enter and remain in outpatient treatment.

Resource parents: Community members attuned to specific community needs identify and assist clients through the Resource Parents program. They "let clients know they have something in common," show respect



for their clients, and "let them know there is someone to care for them." Resource parents are trained to use Healthy Start systems, provide limited case management and a variety of social support services, and help clients with parenting skills. They work to ensure that women receive medical checkups, counseling, drug treatment (if necessary), nutrition guidance, and coupons.

• Take advantage of the special skills of community members through programs such as Resource Parents, in which clients receive assistance from members of the community.

The DC team used the curriculum designed by the National Commission to Prevent Infant Mortality as a core component when developing the training program for Healthy Start resource parents. The team expanded the modules in the National Commission's two-week program and developed some of its own modules. The DC Healthy Start curriculum features a six-week program; however, because even this amount of training time was "not enough," the curriculum also includes weekly and biweekly continuing education classes for resource parents. Service providers and trainers from other facilities teach part of the curriculum, and thus participate in the development of resource parents.

Male involvement: Hatcher stressed the need to involve males in the effort to reduce infant mortality. The message should be: Prevent unwanted pregnancies, and promote responsibility when these pregnancies occur.

Target programs to both males and females, futhers and mothers. Hatcher reinforced the critical need to stress that "Dads have babies, too."

Management and governance

For community residents, health insurance is one of the greatest attractions of being employed by Healthy Start. Through Healthy Start health benefits, some staff received health care through private physicians for the first time. While salaries are "not great," they have enabled some employees to open checking accounts for the first time.



Staff perform well even when they do not have a high school diploma or GED. Hatcher pointed out, as did many other Healthy Start representatives, that all project staff perform equally well regardless of education.

Assess the problem-solving skills of candidates for staff positions, and recognize that people without a high school education or a GED may perform as well as (or better than) those with formal education credentials.

Program supervisors need to be highly skilled managers, especially when staff members are new to the work force.

Place highly skilled managers in supervisory positions, especially when staff from the community do not have substantive working experience.

Goals and regrets

It would have been more useful if the nursing component had been established before the Resource Parents program was begun. While resource parents can make valuable contributions, they require moderate to intensive supervision; without this supervisory component—which can be provided by nurses, social workers, or others—most of the workers are not goal-directed and do not have enough training and skills to manage cases alone. Also, the team regrets that the city's existing public health nursing component could not be integrated with Healthy Start and serve as the manager for Healthy Start's case management component. As DC Healthy Start is administering its own case management component, the structure does not serve one of the team's most important goals, to change systems and institutionalize effective models. DC's Healthy Start team does not want the Initiative to "just be a special project," but to effect lasting changes.

• Focus on original goals and continue to determine new goals. Unless project staff are continually thinking of new ways to improve the program, growth and learning cannot take place.



THE HEALTHY STARY INITIATIVE



NORTHWEST INDIANA PROJECT

Presenter: Velma Strawhun

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 specifically target 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 live births; the Initiative is working to reduce this rate by 50 percent by 1996.

Management and governance

Each of the four cities within the project area has its own health department. Most Healthy Start programs emerged from a preexisting entity; this team developed a separate organization, the Northwest Indiana Health Department Cooperative. The governing board is composed of the mayors of these cities and the county commissioner; the health officers comprise the management team. The consortium includes 20 persons from each county and 20 at-large representatives, for a total membership of 100. Eight committees help guide the project. Currently, the consortium focuses on three key issues: refining the infrastructure, establishing policies and procedures, and ensuring that quality assurance is in place. An active, viable consortium is crucial to the development of the project.

Strawhun described the work at Northwest Indiana Healthy Start as "the best of times and the worst of times." The consortium saw great potential and hope, and recognized that it faced an opportunity to develop a system to improve program outcomes. The consortium also recognized that systems would need to be integrated across municipal. service delivery, and geographic lines. Strawhun affirmed, though, that, in spite of these obstacles, "we can make a difference."

Although turf is an issue for some agencies which are reluctant to work together, many agencies are eager to collaborate and recognize that they cannot be isolated and must expand their services because the need is so great.

Agencies must work together to survive and fulfill community needs.

One-stop shopping

The consortium established one-stop shopping by placing a Healthy Start site in each city, with one central office to handle administration, financial support, public information and education, and transportation issues. Each site offers core services and has the flexibility to determine how it delivers services. One important feature of this Initiative is co-location of services. It is easier for clients to access services if many are offered at one place. WIC





services, well-child care, lead screening, family planning, and substance abuse services are all co-located.

Offer multiple services at one location to encourage clients to use a variety of available services. "Why should consumers have to go look for providers?" asked Strawhun.

Through case management, the local teams conduct risk assessments of clients to determine their medical, social, psychological, and environmental

risk factors. The target population includes pregnant women and children up to one year of age; in addition, the consortium works with adolescents to encourage delaying their first pregnancy. Parenting, Lamaze, and exercise classes are offered. Vitamins donated by pharmaceutical companies are given to pregnant women. Psychological and social services are also offered.

Program initiatives

The Healthy Start Initiative offers a variety of special services, including the following:

"Tot-drop" services: Northwest Indiana sites offer "tot-drop" services to assist pregnant women with children.

• Fulfill clients' child care needs by offering on-site child care.

Outreach: Outreach workers identify clients for the Initiative. The workers have learned to go wherever the target clients are (e.g., laundromats). Plans are under way to offer transportation to Healthy Start sites and physicians' offices to make it easier for clients to keep appointments.

• Do not wait for clients to come to the site—-send outreach workers to find clients in the community.

Resource center: The Healthy Start consortium works with a local college, which has developed a resource center that is open to the Healthy Start consortium. The center provides materials to distribute to clients and serves as a lending library for the community. This successful venture describes an important lesson learned:

• Seek out collaborative relationships with local colleges or universities when feasible.

Although many services are available, clients and providers either do not know about these services or how to access them, or find the services difficult to access. To overcome these barriers, the reference library provides an on-line referral service instead of relying on resource directories, which are outdated immediately.



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Find innovative ways to educate clients and providers about services available in the community. On-line technology is one way of providing both clients and providers with up-to-date information.

School-based clinics: There are school-based clinics in all four cities. A "lunch and learn" program for adolescents with children allows them to talk about their problems and provides support for staying in school. Participants have published a book entitled *Eye on the Circle*, a piece filled with emotion, describing "what was in their guts."

• Focus on adolescents and work within schools.

Collaboration with outside groups

The Northwest Indiana consortium has sought collaborative ties with the four cities, other service agencies, the state, local universities and colleges, and local provider networks.

Local: At the local level, the team works closely with government because the mayors of the four cities are on the Healthy Start governing board. Collaboration with the health departments is fostered because the health officers are on the Healthy Start managing board. This collaboration helped to implement the Genesis system, which allows information from a birth record to be transferred quickly from the hospital to the health department. In addition, the legal entity for the health departments reviews death records for the infant mortality review.

State: The consortium coordinated efforts with the state of Indiana when developing its management information system. The standard MCH fornat was used so that the Healthy Start system could be integrated with the state system, but was expanded by Healthy Start for its own specific data needs. Because of this collaboration, information can be shared easily across agencies, and clients will not have to go through the intake process at each agency. In addition, the state provides pregnancy kits to the sites.



• Explore possibilities for expanded relationships with local and state governments; close collaboration can be valuable.

University: As described above, the Healthy Start team works with a college to support the resource center. In addition, medical students from the Indiana University School of Medicine provide services to assigned clients. The school assigns students to certain families so that the students can act as their advocate.

Provider networks: There was distrust among the providers concerning the scope and purpose of Healthy Start, but collaboration is ongoing and active. Each city has a provider network, and providers are asked to sign an agreement to be a Healthy Start provider.

Future plans

The Northwest Indiana consortium would like to add services at each site.

Expand home visiting: Medicaid pays for only 24 hours in the hospital, so the team wants to conduct visits both before and after the mother's hospital stay.

Address violence: Gary, Indiana, has a high per capita murder rate; the consortium is examining ways to exert a positive impact on this issue.

Establish a Sister Friend program: Volunteers will be recruited from the community as sister friends, providing support and advice to pregnant women and young mothers.

Explore other possibilities: Other ideas include establishing lead screening and smoking cessation projects and providing a child health component.



NEW ORLEANS PROJECT

"Great Expectations"

Presenter: Marsha Broussard

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 government agencies. The Initiative uses a holistic approach to help people change factors that 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 Afrocentric training and orientation program (Communiversity) 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 reduce the high infant mortality rate of 23.3 deaths per 1.000 live births (1984-88). The goal is to reduce this rate by half by 1996.

Identity and community empowerment

The community—both providers and consumers—were attracted to the concept of "Great Expectations." The name is used in different analogies for accomplishments in the community, at the personal level, and at the city and state level.

• Choose a name for the project carefully; it can be a powerful tool. "There is a lot in a name," affirmed Broussard.

Great Expectations has had an active consortium from the beginning. Establishing active Service Area Advisory Councils has been a program priority for the past year. The experienced community organizer contributes to the success of establishing a strong community-based advisory structure. Because the community organizer has an understanding of the community leadership in each of the areas and an appreciation for the political contexts in which they function, she has diffused many potentially inflammatory issues.

© Experienced community organizers can help diffuse many problems before they become disruptive to the program.

Program initiatives

Geographically, the project area encompasses 10 contiguous areas in New Orleans, all of which have inadequate prenatal care services. This region has few providers and lacks a system of coordinated, community-based prenatal care. Before the Healthy Start program began, services were overcentralized at the Charity Hospital facility. Great Expectations intends to expand social and medical services in all 10 service areas.

A Great Expectations needs assessment indicated that a limited infrastructure existed for providing community-based prenatal care. Five community-based health centers are now operating, three of which are recent recipients of funding through Title III, Section 330 of the Public Health Service Act. Great Expectations funding is helping these centers to expand their prenatal and pediatric care services.



In spite of the availability of new funding for medical staff, recruitment of providers has been difficult. Developing a contractual relationship with the two medical centers has enabled the community health centers to increase perinatal staff in the community health centers. The staffing model has included medical center faculty and residents; in addition, midlevel health professionals and four nurse-midwives have joined the staff. While the use of medical center physicians does not meet the long-term goal of establishing a more permanent community-based physician presence, it does help to meet short-term service expansion needs and augment the recruitment process.

Use both long-term and short-term methods to increase the supply of medical providers. One effective method is to seek an ongoing linkage with a medical school.

Accomplishing service expansions in the community health centers has been difficult in almost every center. Simply providing additional medical services has not prepared the centers to handle additional clients. The influx of new providers and clients has increased the stress level and decreased the effectiveness of support staff. In the process of adding physicians to the centers, the Great Expectations team quickly discovered that additional support staff were needed. Some of the centers had not received adequate funding for many years: as a result, they also needed resources dedicated to remodeling facilities, improving computer systems, retraining staff, and providing other supports.

O Plan to spend resources not only on recruiting providers, but also on building the infrastructure needed for service expansion. Increasing medical staff does not automatically result in increased care capacity for health centers that have been poorly funded in the past.

Outreach

A pyramid represents the project's current services. Case management. the core service, lies at the base of the pyramid. A case management site has been established in all communities served by Healthy Start. Outreach is at the next level of the pyramid. As of late 1993, 60 outreach workers, called



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"nanans" (godmothers) and "parrains" (godfathers), had been hired; they are supervised by caseworkers in the 10 sites. Medical services form the third level of the pyramid. The fourth, and final, level is adolescent outreach.

Community input in selecting the outreach workers was a "cumbersome" process." Staff and volunteers "deliberated long and hard" about the appropriate level of input and control the community should exercise in the selection process. In the end, Service Area Advisory Councils were asked to form personnel screening committees to help recruit and interview outreach worker candidates from each of the 10 communities. These councils then made recommendations for outreach workers for their respective communities. Program staff established minimum criteria, participated in the interviews, and made final selections.

Seek community input when recruiting community outreach workers, but maintain control over the process.

Organizing the training for outreach workers has taught the team some lessons about partnerships. To train outreach workers, Great Expectations has formed a partnership with Project Independence and the Orleans Private

Industry Council (OPIC), which is partially funded through the Job Training Partnership Act. Project Independence is a referral source for outreach workers, and has also provided stipends for eligible recruits in the training program. OPIC has funded almost 95 percent of the training for outreach workers; this arrangement has clear benefits for Great Expectations and for OPIC because almost 100 percent of the trainees have been placed.

Coordination and collaboration

The public relations committee has established a partnership with an area television station which is conducting a campaign to promote healthy children. Called "Success by Six," this program produced and aired, free of charge, a promotional piece for Great Expectations.

• A good partner shares fiscal and programmatic responsibilities. To find good partners, identify organizations that have mutual goals.

To aurment the adolescent outreach component of the program. Great Expectations contracted with the National Council of Negro Women to expand their Teen Enlightenment program in schools located within the project area. This program identifies and targets sexually active adolescents for more intensive case management services. The advantage for Great Expectations was that the program had already been developed.

The New Orleans Health Department received funds from the Center for Substance Abuse Treatment to establish a pregnant or postpartum women's residential treatment facility. The plan calls for complete integration with the Great Expectations project, including using Great Expectations case managers (for central intake) and outreach workers. The advisory committee for the program will also become a committee of the consortium. Through this connection, the program can expand resources for a high-risk populations, ease access to other services for these clients, and create a more integrated service system for pregnant or postpartum women who abuse substances.

• Coordinate services with other organizations or publicly financed programs to conserve and expand resources, facilitate access to services, and integrate systems.



Great Expectations has generated several spinoff entities, one of which is the New Orleans Perinatal Task Force. Participants in this successful spinoff include the New Orleans Health Department; the New Orleans Health Corporation; the Louisiana State University and Tulane University medical schools; Excelth, Inc., a new primary care corporation; and the state office of public health. Because Great Expectations mainly serves the same clients, collaboration among these agencies has had many advantages. Examples include increased efficiency through avoiding duplication of services; improved continuity and quality of care for the patients through improvement of referral systems; and enhanced resources available to each organization.

• Collaboration provides opportunities to expand resources and improve quality of care.

Quality assurance

In the early stages of program development, consortium members recognized that there were problems with establishing standards for how services would be provided. Staff initially had a limited view of what the Great Expectations quality assurance program would encompass; however, after deliberation, they expanded the boundaries of the program and defined it broadly. Currently, quality assurance covers three main areas:

- A systemwide assessment of providers who participate in the program, by requiring that all service contractors participate in the quality assurance program and by writing memoranda of agreement with noncontract providers.
- 2. A clinical services component, which consists of medical chart audits, risk assessment review, and protocol reviews. At quality assurance meetings, reports are discussed and correction plans are implemented.
- Outreach and case management components, which are specific to Great Expectations' direct services but also integrated in the overall program.



All Great Expectations employees and contractors are required to participate in a total quality improvement program.

• Make quality assurance a high organizational priority.

Future goals

Broussard summarized the strengths of the New Orleans Healthy Start Initiative: strong leadership and the cultural connection achieved through utilization of outreach workers.

The consortium also faces some challenges. One challenge—identifying creative approaches to accomplishing goals for economic development—is particularly pressing because it is a high priority to communities, but program resources to address this issue are limited.

Service integration is another challenge. Although Great Expectations is a program of the New Orleans Health Department, other health department programs, such as the Well Baby Clinics and the Health for the Homeless programs, have not established the relationships needed to allow clients to achieve the maximum benefit. These linkages will be greatly improved as the outreach workers become fully versed on other health department programs and become effective at making referrals. Great Expectations is also working to establish computer links between the programs; these linkages will enable the team to track and monitor clients more effectively.

QUESTION AND ANSWER PERIOD

Teaching hospitals and continuity of care

A member of the audience noted that continuity of care can be a problem when services are provided by a teaching institution. Broussard responded that a Perinatal Task Force, composed of medical center and clinic staff, helps the consortium address this issue. A portable record system has been



developed to track patients throughout the system. Continuity of care and follow-up are important case management themes. Community health nurses at each site help coordinate care between inpatient and outpatient settings.

• Pay particular attention to issues of continuity of care, especially when the project area includes a teaching hospital.



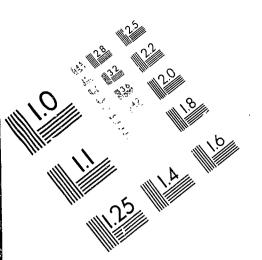
THE HEALTHY STARY INTIAPIVE

BALTIMORE PROJECT

Presenter: Barbara Squires

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 userfriendly 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 nonpregnant women and their families. Through these efforts, the Initiative hopes to reduce by 50 percent the area's high infant mortality rate of 20.1 deaths per 1,000 live births (1984-88), which is higher than the overall rate for the city, and one of the highest among large U.S. cities.

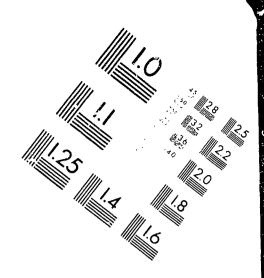


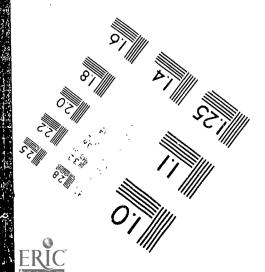




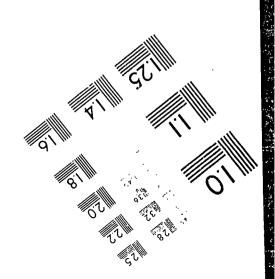
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Management and governance

The management team meets every two weeks to gain understanding of the day-to-day successes and problems of the program.

• Realize that effective project management and accountability are critical to the success of the program.

To achieve a long-lasting reduction in infant mortality, there must be community ownership and systems reform. The Baltimore Healthy Start consortium intends to change the way services are delivered. The consortium provides important guidance to the project; in particular, input from the community is crucial for setting priorities. People in the project area are concerned with finding food and shelter, not necessarily with prenatal care and family planning.

• Recognize the community's priorities and do not impose priorities on the community. These issues must be dealt with before prenatal and pediatric care can be fully addressed.

Housing, for example, is a critical issue in Baltimore. The Baltimore Health Department received a lead abatement grant from the U.S. Department of Housing and Urban Development. The grant serves the same project area as Healthy Start with programs for lead abatement and moderate rehabilitation of housing units.

Program initiatives

Neighborhood health centers serve two of the areas at highest risk within the project site: one is in West Baltimore, and the other is in temporary quarters in the "Middle Fist," an area around the Johns Hopkins University medical institutions. Originally, the consortium hoped to serve 10 areas. When the team did not receive the level of funding anticipated, it had to set priorities. Consequently, two of the highest-risk areas were selected for intensive services and aggressive or treach. Community workers identify at-risk women



and refer them for case management and home visiting services. The consortium has developed protocols and policies to direct interviews with clients. The consortium also has incorporated the home visiting component of the health department's maternal and infant nursing program. Home visitation had been minimal, but the Healthy Start project has integrated and intensified this component.

The project area enjoys an adequate supply of prenatal and pediatric care providers, but services are not well utilized, with poor rates of early entry into prenatal care and poor compliance with visits for well-baby care. The team held focus groups with providers and users to discover their perceptions of the system. Consumers said that they faced long waiting times; were not treated well by providers; thought they were treated differently if they were on medical assistance or had no insurance; had no continuity of care; and faced barriers to access because of a lack of child care and transportation. To address these problems, the consortium has worked with 18 clinics to improve their user-friendliness.

- Ask consumers what they think of the services being provided.

 Using techniques such as focus groups, a team can discover important barriers to the effective use of services.
- Address the user-friendliness of clinics by working directly with service providers to change clinic policies and characteristics.

Baltimore's consortium has established 16 criteria which medical providers must meet to receive funds from Healthy Start. For example, they must decrease waiting times, increase continuity of care, and physically improve reception areas. Another requirement was to involve the fathers. Providers initially found male involvement a foreign idea. Since the fathers did not feel welcome at health centers, the Healthy Start consortium suggested some simple ways to encourage their involvement.

- © Encourage male involvement in a variety of ways: for example, make copies of Sports Illustrated available in the waiting room and display pictures on the wall with positive images of men who are supportive of women.
- Require one male partner prenatal visit and two male partner visits for well-baby care during the first year.



Initially, medical providers were required to institute training to improve staff-patient relations. The consortium thought that clinics would develop their own training program, but found that providers wanted to use techniques developed centrally by Healthy Start. Thus, the consortium has developed a core training module that can be tailored to specific needs.

Outreach

The community must support and participate in Healthy Start programs. In Baltimore, neighborhood health advocates are hired from the community; educational and work histories are not required. The workers are effective, and have had "far more success" than professional staff in bonding with most hers and motivating them to come back for services. Through Project Independence, Healthy Start can hire mothers receiving Aid to Families with Dependent Children (AFDC) assistance in a two-year training capacity, allowing them to receive benefits and needs-based payments.

Outreach staff must be creative, dedicated, and persistent. The Healthy Start tracking system begins when the outreach worker gathers basic information from the client wherever they meet; if the client does not come to the clinic for services within seven days, the outreach worker goes back to the community to find her.

Once a client is identified, it is important to encourage her to come to the clinic and to remove barriers preventing her from accessing services. Consortia should explore innovative ways to encourage mothers to come to the clinics.

- Provide meals at clinics as an incentive to encourage mothers to come to the centers.
- Provide on-site child care, with age-appropriate activities available. Child care makes a "big difference," by allowing more private time for the client and the provider and by decreasing the level of noise and chaos in the reception area.



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Strategies

Despite aggressive outreach. the consortium still finds women relatively late in their pregnancies (4–5 months is the average). Many women do not know they are pregnant or do not confirm their pregnancy until their second trimester. The window of opportunity for engaging pregnant women is very short. While prenatal care should ideally be provided early in the pregnancy, the team often has only four months to serve their clients.

• Plan on having only four or five months to treat pregnant clients (though, ideally, women should begin prenatal care early in pregnancy). Even with aggressive outreach, it is difficult to find women early in their pregnancy.

In addition, the consortium has learned how difficult it is to change behaviors such as substance abuse, smoking, and poor eating habits. Moreover, it is more difficult for someone without opportunities or with multiple risks to change these high-risk behaviors. These changes take time, and often will not occur over the course of the pregnancy.

Therefore. Squires advocates using long-term strategies to treat high-risk women. Programs for pregnant women should not end after one year, but should continue for three years. In this way, future pregnancies will have better outcomes.

Use long-term strategies, and address the needs of nonpregnant and postpartum women as well as pregnant women in order to achieve long-term goals.

These strategies should involve male partners. Men often have very strong influences on the women in Healthy Start programs, and must be involved. The Baltimore area learned this lesson the hard way: the Baltimore Project, which preceded Healthy Start, focused on the mother and baby, but learned that the male partner had a lot of influence. If the information learned in the program differed from what her male partner was saying, the mother would not change. Fathers should not be viewed as extensions of mothers, but as direct clients.

• Involve men in any intervention to address infant mortality.





Successes

It is important to recognize not only Healthy Start's overarching goal of reducing the infant mortality rate, but also the smaller successes en route to the goal. In Baltimore, women set their own objectives and work toward those goals, which range from earning a GED to obtaining job training to retrieving their children from foster care.

• Recognize and honor all kinds of successes, not only the progress toward the main program goal.

QUESTION AND ANSWER PERIOD

Turf issues with neighborhood health centers

A member of the audience asked whether the Baltimore project faced turf issues with the neighborhood health centers in the project area. Medical providers are supportive, responded Squires, particularly since they could not

afford case management and outreach. The Family Support Centers, however, are another entity, and they view this Initiative as a competitor for clients. There are "enough clients," noted Squires, who added that the Healthy Start consortium is enhancing its parenting and family planning components.

Empowerment

Reverend Dye (Pittsburgh consortium) noted that Healthy Start consortia were providing many services, but asked what would happen when the funding for the Initiative ended.

Squires described Baltimore's consortia, which operate at two levels: the project area, and the target area around each center. Target area consortia, which include consumers, community residents, and businesses, meet monthly and discuss the specific parts of the program that they like (or do not like). Through these consortia, there is "buy-in" and support from community members, who discuss the programs at centers and how to find funding beyond the federal appropriations for Healthy Start.

Encourage consortia to discuss the future of the Healthy Start Initiative, and include concrete discussions about searching for alternative funding sources.

Strawhun commented that the Healthy Start consortium in Northwest Indiana supports community forums in the neighborhoods to help people organize. The Sister Friend program provides the community with an opportunity to help itself. The adolescent advisory group works with programs and services that target the adolescent population.

Broussard (New Orleans) said that Great Expectations is working to train the Service Area Advisory Councils, anticipating that they will "move in the direction of creating nonprofit organizations." The Healthy Start team is providing technical assistance to the councils so that they can become 501(c)(3) organizations. In addition, the project is "also trying to incubate some husinesses." to generate long-term prospects for economic development.

Dye stressed the importance of training people in the community to assume responsibility for project functions, so that the health system will remain in place in the community and community members will have



transferable skills. "One of my fears is [that] we're going to do a 'brain-drain,' we're going to do an information drain, we're going to give people great expectations, and then all of a sudden it's going to come crashing down in three or four years."

Retaining AFDC benefits

Brenda Bell-White, director of the Milwaukee project, asked how the Baltimore consortium had arranged for the outreach workers hired by Healthy Start to retain their AFDC benefits. Squires responded that the team had worked with a government office in Baltimore to establish this program. Hiring a neighborhood health advocate would cost \$20,000, which was not affordable; but through Project Independence, the Baltimore Healthy Start Initiative can compensate workers through needs-based payments while workers retain medical assistance, AFDC services, and food stamps. Outreach workers may remain in the program for two years.

1993 Healthy Start Grantee Lessons Learned

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Acronym Key

AFDC Aid to Families with Dependent Children

CHC Community Health Center

CSAP Center for Substance Abuse Prevention

GED General Equivalency Diploma

HIV Human Immunodeficiency Virus

JTPA Job Training Partnership Act

MCH Maternal and Child Health

OPIC Orleans Private Industry Council (New Orleans Healthy Start)

RFP Request for Proposal

USDA U.S. Department of Agriculture

WIC Special Supplemental Food Program for Women, Infants and Children

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