



**National Healthy Start Association, Inc.**

**THE HEALTHY START  
GUIDE TO EFFECTIVE  
COMMUNITY  
INVOLVEMENT**



This research was funded by the Annie E. Casey Foundation. We thank them for their support, but acknowledge that the findings and conclusions presented in this document are those of the authors alone and do not necessarily reflect the opinions of the Foundation.

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**2006**

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## **National Healthy Start Association, Inc.**

### **MISSION STATEMENT**

The mission of the National Healthy Start Association is to promote the development of community-based maternal and child health programs, particularly those addressing the issues of infant mortality, low birthweight and racial disparities in perinatal outcomes. As part of its mission, the NHSA supports the expansion of a wide range of activities and efforts that are rooted in the community and actively involve community residents in their design and implementation.

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### FORWARD

*Spring 2006*

The Board of Directors of the National Healthy Start Association (NHSA) and I are pleased to offer this toolkit, one in a series designed for those who work in the Healthy Start program and for other communities where improving the health of mothers, infants and families is a priority.

The foundation for success in the Healthy Start program has been the conviction, born out by experience, that local communities must be an integral part of any planning and action aimed toward increasing healthy birth outcomes. A publication issued by the Maternal and Child Health Bureau characterized this program as:

- “A community-driven approach that relies on local leadership and widespread collaboration to integrate the vast array of services needed to respond to the broad deprivations that adversely impact community health.
- “A holistic strategy that recognizes that infant mortality, especially in communities where this problem is particularly pernicious, must be addressed within the broader family, community, social, and economic contexts.
- “[Having] an emphasis on innovative approaches to developing coordinated, comprehensive, culturally competent models of health and other support services.”<sup>1</sup>

The National Healthy Start Association is very grateful to the Annie E. Casey Foundation for making funds available for this toolkit. We also wish to thank Mildred Thompson, Oakland, California, the primary author of this toolkit, and Legacy Advisory Committee member Deborah Frazier, the document’s main reviewer.

We welcome your comments and suggestions about this publication, which is also available on our website at [www.healthystartassoc.org](http://www.healthystartassoc.org). Thank you for your continued efforts to reduce racial and ethnic disparities in perinatal health and your work with mothers, children and families!

Belinda Pettiford, President

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<sup>1</sup> *The Healthy Start Initiative: A Community-Driven Approach to Infant Mortality Reduction*, Volume I, “Consortia Development,” 1998, p. 1.





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### Part One: Overview of Healthy Start and Community Consortium

In Part One, we provide information on the history and development of the maternal and child health field.

#### Infant Mortality as a Critical Factor in Reducing Health Disparities

One of the significant distinguishing characteristics of the Health Resources and Services Administration's (HRSA) unique design of the federal Healthy Start Program, in 1991, was its mandate of substantive community involvement, "over the life of the program." Funded programs were required to bring together a broad array of individuals and institutions whose primary purpose would be to serve in an advisory role to recommend policy, services *and* "participate in discussions related to allocation and management of project resources."<sup>2</sup> This bold vision of a new way to reduce

infant mortality was fueled, in part, by the need to find creative approaches to our country's rising infant mortality rates. Traditional strategies, mostly related to increasing access to care, proved less successful than expected in impacting such high numbers of babies dying across our nation's poor inner cities and rural areas lacking layers of infrastructure and resources needed to meet residents' basic needs<sup>3</sup>.

The climate was ripe for change. Maternal and Child Health programs were barely recovering from an epidemic of crack cocaine that resulted in large numbers of babies born to substance abusing women. Unprepared hospitals faced large numbers of abandoned babies. Even more alarming, infant mortality rates soared, while medical and social service organizations scrambled to put in place systems of care to effectively and sensitively meet the challenge.

This was also an era in which increased attention was placed on improving the country's overall rates of health disparities and there was also increased focus on racial and ethnic disparities. People affected by racial inequities also tend to suffer disproportionately from health disparities, economic hardships and lack of access to opportunities that could help create a more level playing field. It was impossible to ignore statistics indicating that infant mortality rates contributed, in large measure, to the ever-widening gap in poor health outcomes between African Americans and Whites. Black babies were dying at rates far greater than the majority population.

Statistics also indicated that other populations were at risk. Some low-income Whites, American Indians and certain Latino populations also suffered from the effects of health disparities, and for some, their rates of infant mortality increased. It was a time for creative solutions to a looming health crisis with its roots deeply embedded in an intricate set of racial, social, political and economic inequities. Communities

#### 1991: The Time was Right for Healthy Start

- U.S. infant mortality rate was rising.
- Traditional strategies to combat infant mortality were not as successful as expected.
- Babies were being born to crack-addicted mothers.
- Black infants were dying at higher rates than other populations.
- There was a new focus on racial and ethnic disparities in health and health care.

<sup>2</sup> HRSA Healthy Start guidance, 1991.

<sup>3</sup> At inception, the nation ranked 22<sup>nd</sup> in developed countries' infant mortality rate.



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faced with high infant mortality also suffered from high rates of poverty, crime, unemployment, poor housing, poor social networks, fragmented service systems, inadequate schools and other environmental factors that significantly compromised not only its members' physical health, but limited their overall quality of life.

Visionaries responsible for crafting the Healthy Start Initiative acknowledged the complex nature of the problem and made as its central focus a community-centered approach to reducing infant mortality. It was quite evident that to achieve lasting, long-term changes, the net should be cast much broader than health providers. Moreover, since the program's focus entailed improved health *and* social conditions, no one sector could realistically meet the wide range of participants' needs. The result was increased interest in engaging community as full partners in the Healthy Start Initiative. It was a solution that simply made sense. Why not invite those most affected to join with health professionals in crafting solutions? The addition of this untapped resource could add immense value and credibility to programs. Further, the decision to identify specific roles and responsibilities for community members and organizations would represent a level of trust in community capacity and a willingness to share power, usually absent in federally funded health initiatives. As the funding agent, the Maternal Child Health Bureau's Division of Healthy Start Programs was also quite deliberate about the high level of community participation expected. This was not intended to be token representation.

#### **Consortia Composition**

The primary vehicle for this high-level community involvement would be a community-centered consortium, a broad partnership with a proposed formula composed of program participants and service providers, including:

- Hospitals
- Public health departments
- Federal Community Health Centers (Primary Care's Section 330 health clinics)
- Local and state agencies responsible for administering block grant programs under Title V
- Social service agencies
- Early intervention programs
- Local businesses
- Political leaders
- Faith-based institutions
- Academic institutions
- Other community and civic organizations serving Healthy Start's target areas

Programs also were accountable for consortium adhering to the racial and cultural diversity of the population served. As a demonstration of the consortia's value to overall program success, funding was tied to consortia stability, composition and effectiveness. Consortia members were to be viewed as an



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advisory body, providing input on innovative program strategies, evaluation planning and assisting in garnering broad community support.

#### **Consortia Structures**

Because of the flexibility allowed in creating its structure, there was quite a variation of consortia structures. In the initial phase of Healthy Start, programs experimented with unique models, seeking to find just the right fit that met the needs of the program, community, consumers and funders. In a 1999 study of nine Healthy Start sites conducted by PolicyLink, a variety of consortia structures were identified<sup>4</sup>. Also explored was the level of community participation in decision-making or governance-level involvement.

Though not a requirement, some sites allowed community members to serve in a governance role by placing them in high-level leadership roles. Some sites had a very strong consumer presence, while others had minimal consumer participation. Of the nine sites studied, more than half had a voice in policy. In one site's consortia, Healthy Start staff were not active participants, allowing for maximum community control. But for some, this arrangement raised questions about the impact of limited access to the consortium by staff. One site initially had two consortia; one for consumers and another for providers. They later merged the two. A few sites used existing committees or task forces already focused on MCH related issues to meet consortia requirements. One interesting model involved a regional approach in which each target area had separate consortia. Another model involved service area councils whose representatives sat on consortia boards and actively participated in policy-making decisions. For many sites, consortia members played no role in governance level decision-making, though they were active in consortia meetings and activities.

An important feature of most Healthy Start sites was the ability to raise awareness about the need for male involvement. Meeting the needs of fathers and other men involved in the lives of Healthy Start participants was felt to be crucial to the success of programs. However, it was through the consortia that sites achieved most success in crafting inventive outreach strategies and mechanisms for sustaining active male participation. At least a third of sites involved in the PolicyLink study focused attention on male involvement by creating male-centered programs whose representatives sat on consortia boards. In some instances, the men's programs were, themselves, considered a type of consortia. They recommended and implemented programs, conducted extensive outreach and joined with others to increase their local and national influence. This extensive outreach and the creation of broad networks with new sectors contributed greatly in not only strengthening Healthy Start programs, but in establishing competency, capacity and leadership within Healthy Start communities.

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<sup>4</sup> *Community Involvement in the Federal Healthy Start Program*, Thompson, Minkler, et al.





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### Part Two: Why Community Involvement is Important: Values and Benefits

Below are some of the potential benefits that can result from meaningful, consistent community involvement.

#### Increased Sense of Program Ownership

Community involvement represents a type of investment in the program. Continued involvement over time creates a sense of shared ownership. This perception of joint partnership between community members and programs is an outcome that many would call success. If provided opportunities for meaningful participation, such as program planning, development of outreach strategies, message development and assessments of consortia or program impact, there is a greater tendency for residents' continued involvement. The addition of respected community members to the consortia can lead to increased credibility and trust by both community members and funders. In fact, through their commitment to the program, community members can assist in fund development activities by working together – before funding ends – to enlist broad community support in sustaining program funding or seeking creative new funding streams.

Having community buy-in also serves as a buffer if outside forces present threats to the program. In addition, government leaders and politicians are often quite eager to listen to and accommodate the needs of community residents and community leaders. By having consumers serve as the public face of the program, its value and impact increases. It results in a “win-win” outcome for all.

#### Individual and Community Benefits

Consortia meetings often serve as opportunities to educate parents and others about contributing causes of infant mortality and provide safe environments to discuss needed individual changes and community-level changes. Important linkages can be made between individual behaviors and maternal and infant outcomes. For example, mothers can learn what happens to their babies if they use drugs, smoke cigarettes or consume alcohol during pregnancy. Parents can learn about alternative disciplining practices or ways to address their anger more appropriately. Healthy Start consortia provide rich opportunities for changing individual behavior that have far-reaching benefits for the entire community.

Equally important, major gaps in community infrastructure can become more visible viewed through the lens of Healthy Start. For example, the addition of resources to support community development efforts signaled a new way to work in Healthy Start communities. Some consortia were able to leverage limited funds to attract new funding streams devoted to making needed community improvements while nurturing important new relationships across sectors seldom involved in health-related programs. Many sites formed partnerships with local business leaders, whose support ranged from monetary contributions and fundraising activities to those who joined with program administrators, participating in public education campaigns.

#### Values and Benefits of Community Involvement

- Sense of program ownership is increased.
- Individuals and communities are strengthened.
- Cultural, racial and class issues are addressed.
- Community needs are reflected.



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#### **Addressing Cultural, Racial and Class Issues**

Healthy Start consortia and program administrators work with others to identify challenges related to race, class and culture. As diverse members work closely together to solve major community problems, tough issues related to race must be sensitively addressed. Many Healthy Start communities have witnessed an increase in Asians, Latinos or other people of color. Efforts must be in place to welcome these new community members, learn about their culture and find areas of commonality. Workshops, seminars and activities can be designed to increase awareness and allow for open dialogue. Facilitated discussions can be helpful in understanding subtle ways that race and class permeates most interpersonal relationships and how its effects impact program and consortia functioning.

#### **Programs Serve as a Reflection of Community Needs**

For many communities, reduced infant mortality was not seen as its top priority for community change. However, by linking infant mortality to their list of community concerns, such as crime and violence, substance abuse, lack of access to services, decent housing and transportation, it is possible to demonstrate a common vision upon which consortia members could work together. Moreover, programs can become quite deliberate in crafting their public information messages to make a clear link between social determinants of health, health disparities and Healthy Start's mission. For example, media messages can be developed demonstrating how domestic violence increases the risk for infant death, and how the use of substances during pregnancy contributes to premature or preventable infant deaths. Thus, Healthy Start could be viewed as a program targeting broad social problems, not just a clinical program with a limited focus on a perceived small segment of the community. Further, demonstrating to community members how Healthy Start can be a vehicle to address major disparities between African Americans and the larger society creates higher interest in community participation.



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## Part Three: What's in it for Them? Effective Community Engagement Recruitment Strategies

Research has shown that actively engaging the community, especially consumers, requires considerable investments of time, effort, commitment and resources. Healthy Start programs confirm that adding community members and consumers slowed down their programs. “Indeed, all observed that involving the community in the program slowed implementation...”<sup>5</sup> Time must be devoted to finding the right mix of individuals, convincing them to become involved, addressing their concerns, often redesigning strategies based on their input and finding non-intrusive ways to monitor their participation.

#### Results of Effective Community Engagement

- Sense of program ownership is increased.
- Program participants are empowered.
- Existing networks are utilized and strengthened.

As a result, the initial speedy timeline imposed by Healthy Start administrators to reduce infant mortality by 50% in five years presented, for some, a serious barrier to consistent, high-level community participation. Legislation in 2000, authorizing the program to remain in place beyond a pilot project, provided a sigh of relief to programs still working to reduce infant mortality, strengthen consortia, evaluate effectiveness and communicate their program impact to others. The ability to take more time to nurture important relationships with consumers, community leaders and organizations was seen as a one of the most critical areas for continued focused attention.

#### Value of Consumer Involvement

The trend toward allowing program participants to have a voice in programs that affect them has become more common recently. At times, funders may have driven this push. However, increasingly programs began to value the contributions of community participation and their involvement was seen less as a result of outside pressures than a need for greater insight in effective program planning and implementation. While both Healthy Start funders and programs agreed on the value of community engagement and sites drafted elaborate plans for such involvement, it became clear – early on – that special attention needed to be placed on developing strategies aimed at successfully involving and *maintaining* the involvement of community members. Other than taking visitors and funders on annual site visits where consumers would be available and often participate in staged events or discussions, previously little effort was placed on substantively involving consumers on a consistent basis over the lifetime of programs.

This new deeper level of participation required a culture change for both programs and consumers. Involving consumers required a unique set of strategies, different approaches and skills than those typically involving generic community outreach activities. Creating a sufficient level of interest, energy, and excitement for the program that results in people *wanting* to become involved is possible. It demands persistence, consistency, humility and delivering a good product. However, once the foundation has been set, such groups have the potential of becoming a powerfully effective and respected organization that

<sup>5</sup> *The Implementation of Healthy Start, Lessons for the Future*, Mathematica Policy Research, HRSA, 1997, p. xv.



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others not only listen to, but seek their input before initiating key strategies. They have now established themselves as the “Go To” organization for the community and the various sectors involved.

Involving community organizations and institutions were often less challenging. Many MCH programs, for example, readily saw the importance of being involved in Healthy Start. Most community-based programs welcomed opportunities to participate in innovative, national programs coming to their communities. Some envisioned the possibility of funding. However, the groups with the most to benefit, though less prepared to participate, were consumers. A central question that may not have been adequately addressed in either program planning or administrative guidance was, “How do we make it happen in a way that everyone benefits?”

Other questions emerged:

- How has it worked in the past?
- What types of strategies are needed for successful outreach?
- What should the roles of consumers be?
- In what ways must programs change to accommodate consumers?
- What types of incentives would motivate their participation?
- Even more important, programs pondered, what are the barriers that prevent their active participation?

“Participants will invest their energy in an organization if they expect to receive some benefits.”<sup>6</sup> Some of the benefits may include:

- Working on causes that have personal and community importance;
- Opportunities for networking and social gatherings;
- Information sharing;
- Personal recognition;
- And a sense of civic participation – wanting to make a difference in their community.

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<sup>6</sup> “Understanding Coalitions and How They Operate as Organizations,” Abraham Wanderman, Robert Goodman, Francis D. Butterfoss, *Community Organizing and Community Building for Health*, Meredith Minkler, Editor, 2005, p. 303.



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One significant challenge for Healthy Start programs is learning how to maximize on these potential benefits while minimizing associated costs. Such cost may be related to helping community members understand the role, purpose *and* limitations of the consortia. For example, although the Healthy Start consortia may acknowledge the underlying causes of infant mortality, they will not be equipped or resourced to intervene in all of the social and environmental factors that contribute to infant mortality.

One of the most important tasks of the consortia is learning how to maintain a delicate balance between meeting the needs of consumers, funders and program administrators. Though not an easy task, a critical objective of community-centered programs such as Healthy Start is to develop more equitable power relationships between community groups and established organizations. There must be a willingness to share power with community groups and consumers. The ultimate role of programs should be to improve the lives of those needing services to such an extent that eventually their need for services diminishes. Achieving that goal will result in true and lasting empowerment.

#### **How to Make it Work: Successful Recruitment Strategies**

##### ***Empowering Program Participants***

There are fewer incentives for involvement more important than knowing that others are interested in what you have to say. People who receive services often have strong opinions about the quality of those services, who provides them and the context in which they are provided.

One of the reasons that focus groups are felt to be critical before initiating new ideas is that people who are most impacted are asked what they think about your idea. Opportunities are presented to really hear how targeted populations perceive your concept and, if necessary, make needed modifications. There is often a feeling of having power, a sense of value, that others want to listen to what you have to say and that you matter. Healthy Start programs are encouraged to seek creative ways to enlist the opinions of consumers.

Conducting quality improvement surveys can be an effective way to surface strong leaders within Healthy Start programs. If surveys are conducted asking for input on services or suggestions for improvements, this can be an effective mechanism for involving program participants, especially if surveys yield constructive criticisms. Taking the time to articulate concerns or complaints could actually indicate a high level of program investment and a willingness to assist with problem solving. This may involve putting contact information on forms that are usually kept confidential. Signs can be posted on bulletin boards indicating that Healthy Start administrators are seeking volunteers for consortia, with an explanation on what the consortia entails. For example, “Want to tell us what you think of our program? Please complete the information on the survey below and let us know if you have suggestions for improvement or if you wish to become involved.”

Leveraging strong relationships with participants can be an effective outreach tool. These relationships are usually built on trust, respect and genuine caring. Often outreach workers, clinicians and others having direct contact with participants have formed strong, trusting relationships and can make recommendations for consortia members based on these relationships. Several goals can be accomplished in targeting specific consumers. For instance, inviting a single mother who may be isolated from social networks to



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join the consortia would serve a dual purpose: she would have a voice in letting her needs be known *and* in possibly helping to shape program interventions. Such involvement can have secondary gains by propelling a typically reserved client into a heightened level of visibility, participation and productivity.

A sure way to recruit new consumers is through word-of-mouth from satisfied consumers. Neighbors sharing stories about the role they are playing in a program geared to reducing the number of babies dying can be a very powerful motivation strategy. Having a consumer deliver the membership pitch at a block party, health fair, church event or other social occasion can result in more positive outcomes than using paid staff, whom community members may feel “are just getting paid” to do the work, rather than being truly invested in the community. Similarly, the use of consumers on public service announcements in any of the various media markets (radio, TV or print media) has proven to be effective for some sites.

#### **Tapping into Existing Networks, Nurturing New Partnerships and Identifying Community Leaders**

##### *Faith-based Organizations*

An effective outreach strategy for attracting key community leaders is through the use of existing networks. For example, appeals for volunteers from neighborhood churches and civic organizations can be a good starting point. Some consortia achieved success by collaborating with popular churches with a track record of neighborhood improvement activities. This strategy can be especially successful if specific services or various options are presented. Requests can be made to utilize church facilities for Healthy Start consortium meetings, adopting specific families who may be experiencing hard times and, of course, requesting a high ranking church representative to hold consortia leadership positions.

##### **Potential Partners**

- Faith-based organizations
- Civic organizations
- Tenant associations
- Political appointees
- Business leaders
- Neighborhood leaders
- Schools and other academic institutions
- Cultural organizations
- Other existing networks

##### *Civic Organizations*

Similarly, fraternities and sororities offer opportunities for meeting their mission of providing service through developing partnerships with local community groups. Often these groups are actively looking for ways to demonstrate that they are successful in community building activities or activities that will improve the lives of community members. Letters requesting the involvement of identified members can be sent. Making presentations at group meetings and appealing for consortia volunteers can produce positive results. This strategy can be used by other civic organizations, such as Boys Clubs, YMCAs and Big Sisters/Big Brothers.

##### *Tenant Associations*

Tenant associations in public housing developments or block clubs are often interested in building partnerships with others who can assist them in advocacy efforts to improve neighborhood conditions. Consortia members can begin attending these meetings, sharing information about what Healthy Start is doing in their community, highlighting common themes and how they can help. This can lead to both Healthy Start representation in their organization and obtaining volunteers for Healthy Start’s consortia.

##### *Political Appointees*



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Requesting community representatives from political leaders can have long-ranging dual benefits. In Healthy Start target areas, programs can request appointees from the City Council, school boards, Boards of Supervisors or other governing bodies. Agreements can be made mandating that appointees meet regularly with the governing group to keep them informed on current Healthy Start activities. This process ensures that political leaders are not only knowledgeable, but have access to Healthy Start decision-making. It also increases the possibility of politicians becoming program champions and spokespersons, and possibly working with program administrators on policy development and advocacy efforts.

#### *Business Leaders*

Appealing to local business leaders about the value of their involvement has created some interesting partnerships and collaborations within Healthy Start programs. Though few may be able to carve out time to regularly attend consortia meetings, business owners may be willing to assist in other ways. For instance, restaurants, supermarkets and corner stores could donate food for consortia meetings. Reputable businesses could be asked to sponsor specific activities or events, or the use of their facility for consortia meetings. Efforts can be made to educate businesses on how Healthy Start's work helps their bottom line – having healthier workers living in healthy, thriving neighborhoods increases their productivity and the health of their workforce.

#### *Neighborhood Leaders*

Often local leaders will surface as a result of their long-term advocacy efforts on behalf of their communities. Although their causes may have focused on ridding the community of crime, grime or violence, it should not take much effort to convince them that Healthy Start's mission is similar to theirs. It is typically not difficult for residents to identify a known and respected person in the community who is willing to stand up for meaningful causes. Many times they have appeared in the media or have been known to attend city council meetings, school board meetings or other events voicing their concerns about unmet community needs. Having such a concerned community spokesperson on the consortia can well position the group to have the kind of community presence needed to accomplish many of the organization's goals.

#### *Schools and Other Academic Institutions*

Involving neighborhood school representatives in Healthy Start's consortia may require focused attention, as these schools may already be burdened with limited resources, reducing violence, improving academic performance and maintaining quality teachers. Nurturing relationships with Assistant Principals and School Nurses may be more productive than initially trying to secure the participation of Principals. Making the case for how working with Healthy Start consortia can assist in accomplishing both the school's mission and Healthy Start's mission could be a good way to approach school staff. Appealing to PTAs for a representative can also be a successful tactic. If the Healthy Start program is located in a region with major colleges or universities, an appeal for their involvement could be related to fostering community-campus partnerships, which fits with the mission of many leading universities.<sup>7</sup>

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<sup>7</sup> Many colleges and universities across the country have been working to establish strong mutually beneficial relationships with community organizations. These community-campus partnerships have resulted in innovative program development, provided critical data and research support to programs and offered opportunities for practice in traditional research centers.



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#### *Outreach to Diverse Populations*

As Healthy Start communities experience changing demographics, it is important to the success of the program to include diverse populations on the consortia. Sometimes this presents unique challenges, as programs may be unprepared to face inherent cultural and language barriers. Healthy Start communities have seen an increase in populations such as Hmong, Central Americans, Eritreans, Mexicans and others. Especially if statistics and other data indicate that these new populations are contributing to rising infant mortality rates, it becomes critical for Healthy Start to seek their participation. One way to outreach to new groups is to make sure that program and recruitment messages reflect the community's changing language and cultural diversity. Included in the messages could be information about consortia meetings. Additionally, programs could conduct consortia meetings in their neighborhoods, as a means of welcoming them into the group.

#### *Other Strategies*

Another strategy that can be undertaken is the use of focus groups, consisting of consumers, community organizations and other key stakeholders, asking their opinions about consortia composition. This can be especially effective if delegations of consumers and program staff join in teams to conduct outreach and recruitment efforts as a result of recommendations from focus groups. Programs can also place advertisements in local media or ask popular radio personalities to assist in promoting the program and participating in consortia outreach efforts.

The examples cited above are offered as possibilities to consider when recruiting community members to participate in Healthy Start consortia. Each community consortia's membership should be driven by the unique characteristics of that community. Recruitment strategies should be tailored to meet each site's needs. Programs should be as creative as possible in attracting the attention of non-typical partners. Look carefully at the rich resources available in your community and think about their possible contributions to the program and ways they could benefit from an association with Healthy Start.



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### Part Four: Steps to Sustaining Community Consortia

It is not enough to finally get community participants to attend meetings. An ongoing challenge is to maintain consistent, active participation. Many programs have suffered under the illusion that once they attracted a good representation of consumers, community members and organizations that their job was mostly done. They've now met program requirements. In reality, the serious job is just beginning.

#### Twelve Key Principles in Sustaining Consortia

1. *Accepting people where they are:* This much overused phrase is still one of the most important principles in effective community engagement. People can only be where they are when you meet them. This means not imposing your values or timelines onto them. Instead, being willing to slow the process down, explain, again, what you may have already explained three times and, if necessary, shift your expectations and timeframes. It also means respectfully listening to another point of view.

2. *Establishing clear goals, objectives, roles and responsibilities:* Everyone

deserves to know where the train is headed, how long it takes to arrive at the destination, who needs to help you get there, how many stops it will take and what they are expected to do once they arrive. Community people want to have an assignment, in clear terms. They deserve to know with whom they are working and toward what goal. It is important to link their task to the program's mission.

3. *Linking program mission to their needs:* Stating clearly, and often repeating, that they are needed to stop too many babies from dying too soon, and to make the community a better place for their children and grandchildren, can be a major motivation force to attract and keep committed community members. They have a clear purpose that guides their involvement and commitment.

4. *Building on community assets:* Even communities plagued with the most distressing social and economic problems still have lots of assets. Highlighting these assets can serve as significant leverage points in building lasting relationships. For instance, acknowledging the strong social networks where neighbors look out for each other, share in childcare and elder care responsibilities, cook for each other or tend neighborhood gardens are all assets that help to stabilize fragmented communities. It helps them remember their strengths.

5. *Creating opportunities for meaningful involvement:* Remember the goal here is substantive participation. This means that thoughtful attention must be placed on ways to make their

#### Twelve Key Principles in Sustaining Consortia

1. Accept people where they are
2. Establish clear goals, objectives, roles and responsibilities
3. Link program mission to needs
4. Build on community assets
5. Create opportunities for meaningful involvement
6. Create clear guidelines about the decision-making process
7. Deliver on promises
8. Address issues related to race and class
9. Create consensus-building techniques
10. Build in opportunities for regular debriefings
11. Monitor and evaluate impact
12. Celebrate successes



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involvement count. Most people want to have clear roles, something they are responsible for that they can own and within their range of capability.

6. *Creating clear guidelines about decision-making process:* Let people know early on in which areas they will have input and which areas are the responsibility of the program office. If there are cloudy areas or room for negotiation, it helps to make this clear.
7. *Delivering on promises:* Caution should be given to avoid overstating what you can and cannot do. Credibility and trust can be lost if programs fail to deliver on promises or commitments.
8. *Addressing issues related to race and class:* Though this is a sensitive topic and discussing it can be uncomfortable, it is critical to address these issues in a constructive manner as they emerge. Since Healthy Start programs mostly involve diverse populations, it is not unusual for racial or class tensions to surface. A trained facilitator or consultant can assist in working through these issues.
9. *Creating consensus-building techniques:* It is important to have established procedures for reaching agreement prior to actually needing them. In problem solving complex issues or areas where key stakeholders may be in dispute, it may take several consortia meetings before agreements can be made. Finding areas in common upon which all can agree or seeking a mutually acceptable compromise requires sensitivity, skill and patience.
10. *Building in opportunities for regular debriefings:* Finding time to just check in on how people are experiencing the consortia is important. This is a good opportunity to again clarify the consortia's mission, goals, objectives and limitations. Program leaders must be willing to listen to the experiences of others. By engaging in active listening and honest dialogue, trusting, lasting relationships are formed.
11. *Monitoring and evaluating impact:* Building in mechanisms to determine how well the consortia is functioning and being willing to make necessary modifications demonstrates to members the program's accountability to them and to the community.
12. *Celebrating successes:* Programs should not minimize the need to celebrate successes of both consortia members and the consortia as a whole. Having press conferences and media coverage of special events increases the consortia's value and visibility in the community. Community celebrations can be an effective tool to inform the public of the consortia's impact and can also act as a powerful stimulant to maintain enthusiasm and vibrancy of members.



## **Part V: Avoiding Pitfalls and Landmines: Challenges in Sustaining Community Involvement**

Although some of these landmines and pitfalls were referenced in previous sections of the toolkit, they are mentioned again in this section because of the seriousness in which they should be regarded. Lack of attention to these details can result in significant derailment of the consortia.

- 1. Be aware of time constraints:* It is important to make clear up front what type of time commitments are being requested so that there are no surprises. Often people sign up for what they think is a one-time meeting, only to learn later that they are expected to participate for one or two years. People should also be told how long meetings will last. Remember, attending meetings on a regular basis is not usually a part of consumer's daily routine. Spending several hours in meetings may not rise to the top of their list of priorities when families are juggling the complexities of basic life pressures.
- 2. Acknowledge and mediate power dynamics:* An important point to remember while working in community engagement initiatives is that there is not one homogenous entity called "the community." As a result, programs must work effectively with various personality types and tensions that may surface from racial, ethnic and class differences and individual hidden agendas. Being conscious of what these characteristics look like below the surface requires skill and astute perception. For example, providers should be discouraged from using excessive jargon in meetings with consumers. It has the potential of making one group appear smarter or more in control than another group. Similarly, providers may feel intimidated by community members who consistently use the consortia as a platform for their personal interests. Setting the stage early – with ground rules, if necessary – helps to maintain a climate where every voice is respected and sensitive issues are dealt with fairly.
- 3. Lack of administrative or institutional support for consortia:* A key point here is to have agreements in place that outline the level of support needed to maintain a strong consortium. Dedicated staff time is required to continue recruitment efforts, make follow-up calls to members who may be inconsistent in attendance, in securing needed transportation for members to attend meetings and for following through on decisions made by consortia. Persons staffing consortia and related community outreach activities are often some of the first positions to be eliminated during tight budget cuts. Having funding that allows for food and childcare at meetings also helps as incentives. Sites are encouraged to be creative in offering non-monetary rewards for attending consortia meetings and in finding ways to retain critical staffing during fiscal crises.
- 4. Unresolved racial and class differences:* Not addressing racial and class issues can slowly diminish the power and effectiveness of consortia. If possible, identify guiding principles up front that will assist in navigating through tough situations. As mentioned above, programs may need to seek

### **Challenges to be Overcome**

- Time constraints
- Power dynamics
- Staff support
- Racial and class differences
- Consortia members' experience and training



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outside help to work through some of the challenges. The ability to remain neutral in the midst of such challenges, while at the same time confronting the problem, may require a level of skill, sensitivity and training for which some programs may not be prepared. Again, recognizing underlying challenges or potential challenges early on could go a long way in maintaining the full group's respect. For example, how prepared will consortia members be in receiving non-English speaking members in the consortia? How will a project director mediate a situation where a consumer who felt disrespected in a consortia meeting makes a complaint against a worker? Having a safe space carved out to talk freely and honestly about potential and experienced challenges is critical.

5. *Lack of training for consortia members:* Although all consortia members would benefit from training, extra attention should be placed on training community members and consumers. Representatives from organizations, institutions and businesses often have far more experience attending meetings and participating in collaborations and partnerships than consumers. In an attempt to level the playing field and increase capacity of community residents and program participants, trainings should be offered, ideally prior to joining consortia. Another suggestion would be to require trainings for all consortia members regardless of prior experience so that everyone operates under the same set of assumptions and guidelines. To better prepare members to participate on consortia and to increase the possibility of a positive consortia experience, a series of trainings are recommended.

#### **Suggested Content Areas for Training**

- Leadership development
- Meeting facilitation
- Consortia development
- Conflict resolution
- Communication skill building: spokesperson training, crisis communication, public speaking
- Community organizing/community mobilization techniques
- Cultural humility<sup>8</sup>
- Community needs assessment process/Community-Based Participatory Research<sup>9</sup> (community as evaluators)

<sup>8</sup> Cultural humility includes principles that expand the concept of cultural competence and focuses on incorporating lifelong learning and self reflection geared to redressing typical power imbalances.

<sup>9</sup> Community-Based Participatory Research is an orientation to research that seeks to create a balance between research and action by actively engaging community members in the research process. Its ideal outcomes results in increased capacity building by community members and researchers.



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## Part Six: Evaluating Community Involvement Effectiveness

Attempts to evaluate the impact of community involvement on reducing infant mortality may be difficult to measure, but it may be possible to assess the role of community participants on consortia functioning.

#### Key Questions That Need to be Asked

- What are the indicators affirming that community involvement makes a difference in successful consortia outcomes?
- Why does consumer participation matter?
- Does investment of time, resources and training result in equivalent gains? And if so, what are the tangible gains and how substantive and long lasting will they be?

Researchers have been trying to answer these important questions for many years in programs, like Healthy Start, that require community involvement. There are no easy answers. However, there are questions that can be considered when trying to deepen your understanding in this emerging field:

1. In what ways have consortia changed practices or policies as a result of community participation?
2. Is it possible to track programs that resulted from recommendations made by community members? If so, what were the programs and outcomes?
3. Have there been increased public recognition and visibility of the program or consortia as a result of community participation?
4. Have consortia participated in policy change on a local, statewide or national level as a result of consortia participation?
5. Have former consortia members obtained new skills that were transferred into new jobs, the creation of businesses or did they obtain political appointments as a result of consortia participation?
6. Has there been an increase in civic participation by former or current consortia members?
7. Have consortia members begun to address other community problems, other than infant mortality, as result of consortia involvement?

With the assistance of affiliated researchers, Healthy Start programs can begin to shape their evaluations to address some of these questions. As noted above, community members, including consortia representatives, could also be encouraged and trained to assist in evaluation efforts through models such as the Community-Based Participatory Research strategies. At its core, these types of evaluations work with community members to build their capacity to participate in research and evaluation techniques.



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In the PolicyLink study on the impact of community involvement in nine Healthy Start sites, published in 2000, program administrators and consortia leaders determined that sustained community involvement resulted in the following benefits:<sup>10</sup>

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

#### **Achieving Evaluation Goals and Resources Needed**

If funding could be secured, programs could benefit from learning if these gains are still intact in the nine sites studied. Moreover, an assessment of programs not included in the original study could yield additional benefits. Another option for sharing this information would be to create peer-mentoring relationships among programs, creating opportunities at Healthy Start annual meetings, for programs to share "lessons learned." Programs with demonstrated success could tailor a workshop on how they were able to increase community participation. Even more important, programs could be encouraged to write articles for academic journals or present their model at national conferences, such as the American Public Health Association meetings. Others in the field, struggling with the same issues, would benefit from Healthy Start's years of experiences and lessons learned.

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<sup>10</sup> *Community Involvement in the Federal Healthy Start Program*, Thompson, Minkler, et al.



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#### Part Seven: Conclusion

Healthy Start programs have enjoyed a rich history of implementing strategies to reduce infant mortality since its inception in 1991. After more than a decade of doing this work, programs have amassed a wide range of competencies, faced challenging obstacles, demonstrated amazing resilience, created national models, formed strong collaborative partnerships *and* assisted in the reduction of our country's high infant mortality rates.

A contributing factor in their success and longevity has been the way they do their work. Healthy Start has demonstrated a key distinction among programs working with community members. The program is based on a model of being “community-centered,” rather than “community-based.” The difference is not simply locating a program in the community and hoping they come. It is making the community the center focus of their work. It is about taking the time to create full partnerships with community members so that they take ownership of the program and can act as champions and buffers.

Still, there is more to learn. As contextual changes continue to occur, both nationally and internationally, including a rapidly changing political landscape, economic uncertainties and demographic shifts, it is even more crucial that programs learn ways to work comfortably, in partnership with community. This toolkit is designed to assist programs in meeting their needs for community involvement, not because it is a mandate, but because it is their desire.





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## **Appendix**





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