

**Evaluation of the ZAP Asthma Project  
Contract: 200-96-0598, Task 14**

**Final Report**

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# Executive Summary

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## I. Background and History

ZAP Asthma is a complex public-private partnership in Atlanta focused on reducing the incidence of negative health outcomes associated with pediatric asthma. ZAP Asthma's goal is to demonstrate the effectiveness of environmental control and health education strategies to decrease asthma morbidity and mortality in the Atlanta Empowerment Zone. The initiative presumes that extensive collaboration between low-income communities most affected by pediatric asthma, health care providers, and public health decision makers and researchers will produce improvements in health that none of the partners could hope to achieve working independently. A key component of this initiative, particularly the health education strategies, lies in community engagement.

A consortium of 18 partners, including the Rollins School of Public Health at Emory University in Atlanta, the Atlanta Empowerment Zone Corporation and the related Community Empowerment Advisory Board, the Centers for Disease Control and Prevention, the American Association of Health Plans, six area managed care organizations, the American Lung Association of Georgia, the Environmental Justice Center of Clark Atlanta University, Southwest Hospital and Medical Center, and public safety net providers (e.g., Fulton County Health Department and Grady Health Systems), participated in varying degrees in the initial conception of the ZAP Asthma Project in 1995 and its subsequent evolution. The project officially began operation as ZAP Asthma when bylaws were signed in January 1997.

Representatives from these 18 different organizations have come together to create a consortium that serves as the governance structure known as the Board of Directors. This governance structure is responsible for making policy and, to a lesser extent, operational decisions for ZAP. To minimize the possibility that partners who control the purse strings would have an inordinate amount of influence in policy and operational decisions, a separate 501(c)(3) was established to manage fiduciary responsibilities.

The management of day-to-day activities falls under the purview of the Executive Office, which currently consists of two CDC-funded staff who function as program managers and divide the responsibilities previously managed by one of the founders of the ZAP initiative until his untimely death. The Executive Office is primarily responsible for managing five functional areas:

- ❑ Health education, health promotion, health communication & public affairs
- ❑ Clinical interventions
- ❑ Prevention interventions
- ❑ Evaluation
- ❑ Community development and training

In addition to their governance responsibilities, partner organizations contributed expertise and financial and in-kind resources to the aforementioned functional areas.

Another important component of the governance structure is the Executive Committee, which provides oversight to the Executive Office and functions as a liaison between the Executive Office and the Board. Although a core group of partners, including the CDC and one representative from the HMOs, participate on the Executive Committee, meetings are open to all interested partners.

## **The Science Protocol**

At the heart of ZAP Asthma is a research study designed to test the effectiveness of controlling environmental triggers, such as dust mites and cockroaches, as a means of improving health status and decreasing the morbidity and financial costs associated with pediatric asthma in the Atlanta Empowerment Zone. Central to the research design is a group of Community Health Workers (CHWs) who are community residents trained by ZAP Asthma to go into families' homes to deliver an intervention consisting of roach eradication, professional house cleaning, and bedding and pillow encasing as well as health education and promotion, including smoking cessation when necessary. CHWs are also responsible for recruiting children from the emergency room, and for in-home data collection, such as administering surveys and collecting dust samples, in addition to their expanded duties of outreach and health education for the larger community.

Originally 400 children with asthma between the ages of 5 and 12 who live in the Atlanta Empowerment Zone, Southwest Atlanta corridor, and linkage communities, and who are not involved in other asthma studies, were targeted for enrollment. This target number, based on results from similar environmental control studies, was thought to be a feasible and realistic sample size to detect any changes that may be due to the protocol. Initially, the 400 children were to be randomized into two groups of 200 children each. The first group was to receive the environmental interventions in the home under the supervision of the CHWs. The second group of children was to serve as controls for the first group; however, they would be eligible to receive the same interventions 22 months after enrollment of the first group.

Several changes occurred to the research protocol over the life of the project. Most significantly, in August 1999, in response to lower-than-expected recruitment and retention numbers, the wait-listed control group was converted into an experimental group. As a result, the study would utilize a pre-post test design instead of the more rigorous individual randomized control study. This pre-post test design was projected to reduce the number of families required to perform a valid and reliable analysis from 400 to 120. In February 2000, when it became apparent that even these numbers would not be reached, the Institutional Review Board at the CDC withdrew its approval for the study. Although analysis of data collected on previously enrolled families continues, future data collection has been terminated.

In order to determine the success of the environmental protocol, several outcome measures have been tracked and currently are being evaluated by the scientists in charge of the research protocol. These measures fall into the following clusters: environmental; morbidity; health status; prevention effectiveness/economic analysis; and process which includes increases in knowledge about asthma and improved access to care.

In September 1998, CDC commissioned ORC Macro to conduct an evaluation of the evolution of the consortium and the CHW role. In particular, the study questions included:

- Evolution of the consortium
  - (How) did disparate organizational “players” become an active inter-organizational collaborative?
  - (How) did the inter-organizational collaborative engage and interact with the community in an effective way?
  - (How) did the collaborative approach lead to community empowerment?
  - (How) did the collaborative approach lead to system improvement and capacity building at the community level?
  
- Evolution of the CHW role
  - What role did CHWs play?
  - (How) did use of CHWs contribute to project participants learning more about their child’s disease and gaining self-management skills?

## II. Methods

At the start of the project, ORC Macro staff reviewed documents from prior studies of ZAP Asthma and internal documents. These included focus groups sponsored by independent organizations such as the Soap and Detergent Association and the Center for Health Systems Research and Analysis and notes from a facilitated strategic planning retreat held in November 1997. In addition, ORC Macro staff held discussions with researchers intending to undertake studies of other aspects of ZAP Asthma. Of most relevance to the ORC Macro evaluation is a study by Research Triangle Institute (RTI) entitled the *Evaluation of the Asthma Initiative Partnership Development*.<sup>1</sup> The report focused on the development of the consortium and was based on interviews, document review, and observation with consortium participants conducted during late 1996.

Early in the project and based on the review of the RTI report and other findings, ORC Macro staff conducted in-person and telephone interviews with 25 ZAP Asthma board members, staff members, and community representatives. The purpose of these interviews was to gain a more complete understanding of ZAP Asthma’s goals, history and implementation challenges as well as to help ORC Macro understand what was expected from the evaluation and clarify any misperceptions about the focus of the evaluation. A copy of the interview instrument is included in [Appendix A](#).

A logic model, a graphical representation of the relationship between the different components of ZAP Asthma and the expected short-, intermediate-, and long-term outcomes, was developed based on document reviews and interviews. The logic model also helped determine the most appropriate data collection methods for the study given the key study questions. A copy of this logic model is in [Appendix B](#).

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<sup>1</sup> Griffith, JD, and Lux, L. *Evaluation of the Asthma Initiative Partnership Development*. Research Triangle Institute, January 1997.

Followup one-on-one, telephone-based interviews with partners, staff, and community members were also conducted. The questions, a more in-depth exploration of the workings of the collaborative consortium, the role of CHWs, and the future of ZAP Asthma, were formalized into 39 Likert scale items and a series of open-ended questions. These followup interviews were conducted in early fall 1999 with 11 partners and 11 staff members. In addition, shorter versions were conducted with six individuals in the community who were familiar with ZAP but not considered to be partners. These individuals are referred to as community contacts. A copy of the instruments and the persons interviewed is available in [Appendix C](#).

A separate, more in-depth data collection effort to understand the role and contributions of CHWs consisting of participant observation, individual interviews, and record review was also conducted. Data collection occurred between June and October 1999. The complete findings of this research are included in a separate report which serves as a technical appendix to this final report.<sup>2</sup>

Focus groups with family members as well as key stakeholders, including community-based physicians and HMO representatives, were also conducted to gain insight into why families left the research protocol and what can be done to improve both recruitment and retention and to identify which aspects of ZAP Asthma physicians and HMOs are most interested in incorporating into the way they deliver services, respectively. The family focus group and two stakeholder groups were conducted in February 1999. A protocol for the family focus groups is included in [Appendix D](#). A protocol for the provider discussion groups is included in [Appendix E](#).

### **III. Findings**

The findings from all the data collection activities were integrated and organized into the following six categories: ZAP Asthma's intended objectives, inter-organizational collaboration, intra-organizational collaboration, community empowerment and capacity building, the role of CHWs, and the future of ZAP Asthma. A detailed discussion of each of these areas and how the different data collection activities informed them is available in the full report. The following section summarizes these findings as they pertain to the major study questions of the ORC Macro evaluation.

#### **A. ZAP Asthma's Objectives and Purpose**

In organizational theory, having shared understanding, vision, and approach to the problem is key to becoming an active inter-organizational collaborative. In ZAP Asthma, fissures in vision and approach to the problem of pediatric asthma were apparent early on. For some partners, ZAP Asthma was the research protocol. In the best case, ZAP Asthma was viewed as an effort to test the effectiveness of an environmental intervention and training of families on the intervention as a method of providing asthma self-management skills in the home. At worst, the requirements reduced the front-line staff role to one of data collection to support the demands of the research protocol. In either case, this vision was much more narrow than its competitor, which viewed ZAP Asthma as an instrument for community engagement, empowerment, and even economic revival. At its most "extreme" this vision of ZAP Asthma was not about asthma at all, but, rather,

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<sup>2</sup> Friedlob, A. Use of community health workers in ZAP Asthma: Observations and lessons learned. Citizen Science. May 5, 2000.

used asthma as a platform for these larger goals. Key to this vision was leaving a legacy of relationships, capacity, skills, and structure that could be used by ZAP Asthma (as a continuing entity) or others, preferably from the community, to address other issues. While the learning of families in the home was important in this vision, it was somewhat secondary to more “population-based” orientations such as bringing diverse stakeholders together in a shared vision, and building relationships between the community and institutions and among institutions.

By the time of the followup interviews, most respondents felt that ZAP Asthma had made considerable progress toward finding a common ground. Interestingly, many pointed to a crisis in recruitment and retention of study participants for the protocol as the seminal event that brought the partners closer in terms of unified vision. The crisis allowed for an airing of issues, and resulted in renewed commitment to the protocol and its success.

## **B. Inter-Organizational Processes**

Respondents were struck by the complexity of governing a wide-ranging collaborative like ZAP Asthma and the challenges ZAP faced in intra-organizational governance. Intra-organizational governance was the area in which staff and partner perceptions varied most significantly, with staff generally painting a more negative picture of these relationships than did partners. For many staff respondents, the Executive Committee was perceived to be the real source of power and authority in ZAP Asthma. Although respondents from the board acknowledged the importance of the Executive Committee, they felt its role was appropriate and necessary in order to provide the type of oversight needed for such an unwieldy enterprise. Staff respondents were more likely to express dissatisfaction with this arrangement. Staff viewed the Executive Committee as too involved in operational decisions, which compromised the ability of staff to be flexible and make operating decisions in a timely fashion. In addition, the Executive Committee was seen as not effectively including staff in decisions, although there was a sense that these mechanisms were improving.

## **C. Intra-Organizational Processes**

In general, respondents agreed that ZAP Asthma did a good job of engaging community leadership, especially in the beginning of the project. However, there was less successful engagement of community organizations and residents, although this was seen as increasing and improving in some cases, such as the faith community. ZAP Asthma was scored even lower by respondents on engagement of the average community resident. CHWs were seen by some as an example of engagement of the community, since they were drawn from the community, but others pointed out that, as employees, it was difficult to see them as examples of engaged community members, although they certainly served as a major channel between ZAP Asthma and the community. Respondents agree that engagement and interaction with the community were constrained by low visibility due to lack of resources for marketing and public relations.

#### **D. Community Engagement and Capacity Building**

“Empowerment” as a term is used broadly and loosely. For the purposes of this project and the evaluation, it is defined as the ability of the community to play a significant role as a partner in a similar endeavor, even if it did not implement the endeavor on its own. Defined in that more limited way, respondents could point to important community-institutional relationships that ZAP Asthma has created and to spillover of ZAP Asthma to self-organizing efforts like support groups and camps. However, most indicated that the “jury was still out” on the degree to which these efforts would live on after ZAP Asthma. In particular, respondents indicated that fiscal and organizational issues diverted ZAP Asthma from the proper succession planning that would be needed to ensure a community legacy.

The CHWs are seen as anxious to carry on aspects of ZAP Asthma’s work. Since CHWs live in the area and would like to continue to operate in the community, that is seen by some respondents as evidence of community empowerment.

#### **E. Indicator Progression**

While the results of the science protocol have not yet been analyzed, and CHWs’ success in entering homes has been mixed, most respondents, and participants in the focus groups of families and providers, saw the CHWs as the main system improvement resulting from ZAP Asthma. However, this presumes and requires that the CHWs are maintained and mainstreamed after ZAP Asthma funding is exhausted.

Other potential system improvements in the community were not realized. In particular, while ZAP Asthma may have influenced health providers, at least in the short-term, few community health providers were among the group of engaged health providers. Again, respondents pointed to missed commitments and lack of resources as the reason why fewer system improvements were realized.

#### **F. Role of CHWs**

Ultimately, the analysis of data from the science protocol will be necessary to determine the effectiveness of CHWs. Information from family focus groups indicates that CHWs were seen as adding value to family efforts to learn self-management skills. Also, both staff and partner respondents indicated that ZAP Asthma has made great strides in helping families address their child’s asthma and other health problems. The provider focus groups clearly indicated interest in the CHW model for a wide variety of illnesses and issues.

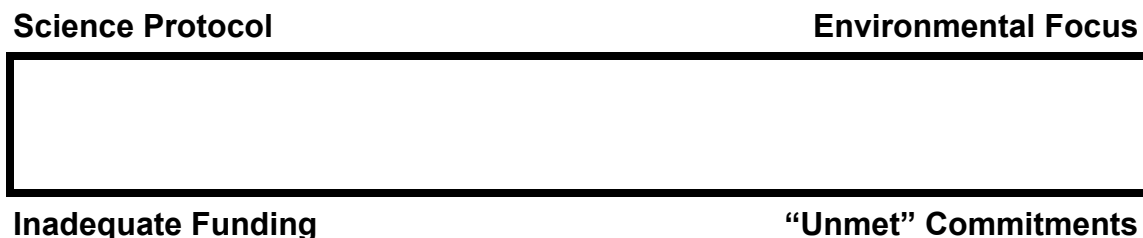
The qualitative research done with the CHWs was not, by definition, able to address the question of effectiveness directly. However, the findings indicated that CHWs were effective at using the skills envisioned by their role. Moreover, CHWs wanted to do more, not less, with families, and believed their ability to help families was constrained by focusing their efforts on the requirements of the science protocol. Indeed, most CHWs stepped outside the role and took on expanded duties. The qualitative research indicated that CHWs *as a group* were effective at both the core and expanded duties.



#### IV. Conclusions and Lessons

This section presents underlying patterns visible in the results of the various data collections and also outlines lessons for those seeking to undertake an effort similar to ZAP Asthma.

The obstacles that face ZAP Asthma and constrain its implementation can be represented as an “iron rectangle.” That is, while each factor is an obstacle in its own right, the four factors work together like points on an iron rectangle, reinforcing and constraining each other. One point cannot be moved without changes in the other points, making change particularly difficult. This is especially true given the environment in which the “iron rectangle” is embedded. In the case of ZAP Asthma, the four points on the rectangle are



The four constraints taken as a group acted in concert such that any solution to one constraint ran up against one or more of the other three. Furthermore, the obstacles that form the iron rectangle were embedded in a social environment made complex by the multiple and interrelated needs of ZAP Asthma’s families and the communities in which they lived.

- The **science protocol** and its requirements placed CHWs primarily into data collection roles. This caused conflict for them in the face of the multiple social and economic needs of the ZAP Asthma families. The chosen science protocol also missed potential opportunities to encompass some of the larger community empowerment/capacity building aspects of ZAP Asthma. Although the missed opportunities were attributed to a fissure between science and service, a different protocol that allowed for integration of community and individual goals, might have resulted in a more “united front” by ZAP Asthma stakeholders and less role conflict for CHWs because the project would be viewed as more comprehensively addressing the needs of families. This role conflict was exacerbated by . . .
  
- The **environmental focus** which, while justified, caused similar role conflicts for CHWs and staff because it focused attention on housekeeping and other household behaviors of families without effectively addressing the larger social and economic needs that rendered families unable to adhere to the environmental focus. While this role conflict certainly was exacerbated by the science protocol, it would have existed without it. ZAP Asthma’s target population had complicated needs and CHWs, who were drawn from the community and saw themselves in “helping” roles, felt constrained by the narrowness of the environmental focus and their primary roles of data collector. The CHWs might have felt less constrained if they saw other activities directed at the broader needs of the families and the community, but . . .

- **Missed/misunderstood commitments** meant that important aspects of the ZAP Asthma model were not implemented as initially envisioned. By default, this put pressure on ZAP Asthma staff to expand their efforts beyond their data collection roles to fill in these gaps. Efforts such as community outreach, health education, and provider education were to be led by specific partners or other allies, but were not. While the original intent of ZAP Asthma was to involve ZAP Asthma staff and CHWs in these activities, it certainly was not intended that they do this alone. By default, these activities fell to them in addition to their existing duties. Some of these activities could have been transferred to new staff or outsourced to contractors, but. . .
- **Inadequate funding** meant that ZAP Asthma constantly had to play “catch up” financially to meet even its basic core commitments. This diverted its attention away from larger community goals and also precluded solutions, such as more staff, that would have eased role conflicts between the science protocol and the larger community legacy.

These four aspects of the project, and the fact they were overlaid on a complicated socioeconomic environment, are at the root of most of ZAP Asthma’s challenges. The key to the next ZAP Asthma-like effort is to address these adequately up front. Some lessons include:

**1. Watch out for “fissures” in vision. Do not move forward without a shared vision.**

In this case, the fissure was between the science and the larger community visions of ZAP Asthma. While a research protocol in a community project is uncommon and, perhaps, undoable, there will be other fissures to take its place on the next ZAP Asthma. The lesson from ZAP Asthma is that these fissures must be identified, confronted, and resolved early in the project.

In this case, the fissure was early and deep. The resulting conflicts, tension, and mistrust cost the project perhaps a year and led to independent, almost hermetically sealed, competing versions of what ZAP Asthma was and what its goals should be. Part of the fissure was ascribable to the final choice of protocol design. While there was talk initially of a science protocol that would be more open to larger community outcomes, the unfortunate and unavoidable departure of key research staff led to a succession of PI staff with more traditional, and narrower, views of how the science protocol should be implemented. As a result, the two competing visions of ZAP Asthma were never fully reconciled.

While the two visions might have been hard to reconcile under any circumstances, clearly, the final protocol design, and its concomitant processes for recruitment, exacerbated the division. For example, the use of the ER as the recruiting venue, while an effective way to find those with severe asthma, made it hard to link efforts with families to efforts with community institutions such as churches, schools, community-based organizations, and merchants that might have supported the efforts of families. If the protocol had focused on clusters of cases in neighborhoods or schools instead, it might have more closely aligned the “community vision” activities such as support groups in schools, health fairs, and neighborhood groups, with the intent of the research protocol to train the families of asthmatic children.

## **2. Expect complexity.**

In the second round of interviews, when partners were asked to reflect on their experience and what they had learned, most were surprised by the complexity at all levels of the project, including

- Complexity of families' lives, particularly those in the inner-city who often face competing demands that limit their ability to participate at desired and expected levels in a community-based initiative. Expectations for family participation may need to be adjusted in accordance to these competing demands. Families often need incentives that encourage them to participate despite these competing demands. However, these incentives do not always need to be financial. For some of the families in ZAP Asthma, gaining knowledge on how to control their child's asthma and the roach eradication were enough. But efforts with many other families would have benefited from additional incentives. The project must be open to considering a wide array of incentives and to using different approaches.
- Complex, interlocking nature of problems in the inner-city often means first solving several other problems that directly influence or impact the one problem you are trying to solve. Without recognition of the interdependent nature of these problems, insufficient resources will be committed and/or key partners will be left out of the collaboration. For example, while asthma manifests itself as a health issue, ZAP Asthma addressed root causes in the home. However, families' ability to address the home environment was constrained by the fact they lived in public housing. Hence, a key partner would have been the housing authority.
- Complexity of defining a collaborative the governance structure that would address the needs of ZAP Asthma, an initiative that integrated science and service, public and private sectors, and institutional and community sectors, without undue time commitments was a challenge. Engaging partners in a collaborative is a continuous activity that may take various forms throughout the life of the project. It should not be assumed that because partners are at the table, efforts to engage them are no longer needed. Partners may need guidance in how to make the most effective contribution to the collaborative.

## **3. Define the “community.”**

The definition of “community” includes elected officials, local merchants, civic and religious leaders, schools, hospitals, local physicians, and other professionals. Efforts should be made at the beginning of the project to determine which aspects of the community are most important to the success of the project. Once this determination is made, sufficient resources, including time and manpower, need to be committed to engaging those aspects. ZAP Asthma, as reported by partners, staff, and community contacts, initially did a good job of engaging community leaders, but efforts to engage community physicians, community organizations, and residents fell prey to fiscal crises.

**4. Lower expectations.**

Given the complexity of the effort, all partners need to understand that outcomes are long-term and that early stages of the project may result in mainly process improvements. These alone are essential, in that they may be levers to achieve long-term outcomes. For example, addressing asthma in inner-city populations cannot be divorced from the multiple and complex issues in the lives of those whom ZAP Asthma was trying to serve. For ZAP Asthma, expectations by some partners of significant changes in health outcomes of families or even revenue/profit generation were naive and unrealistic. Empowering families and the community to address issues like asthma is a journey with a long-term destination. Partners must learn to appreciate short-term process goals such as building social capital and trusting relationships as useful ends in themselves as well as the necessary “platform” for the desired outcomes.

**5. Roles and responsibilities of partners need to be spelled out up front.**

ZAP Asthma suffered from missed or unmet commitments due in part to a lack of understanding by partners of their role and responsibilities. Because the vision of the project was evolving, so was the role of the partners. In time, for some partners, the roles evolved into something different than their original expectations, leaving some partners unable to meet commitments they may not have realized they had made.

Discussion about what is expected from individual partners and the collaborative as a whole helps partners make realistic commitments, both tangible and intangible, to the collaborative. It also helps establish trust between the partners when everyone knows and understands his/her own role and the role of others. Partners have more authority to hold each other accountable and can create a system of checks and balances. They also have a greater sense of buy-in to the project when they know what is expected of them. Partners are also more likely to invest resources when they know there is accountability.

**6. Back up roles and responsibilities with tangible exhibition of commitment up front. Get assurance of enough funds at the start.**

No one thing constrained ZAP Asthma more than the lack of adequate resources up front. All other points on the “iron rectangle” could have been addressed had funds been available to hire staff or bring in expertise to bolster or supplement core staff efforts. Instead, the constant sense of fiscal crisis diverted attention from larger goals to protection of the “vital organs”—the core science protocol and environmental intervention. In ZAP Asthma’s case, the lack of resources is directly related to the points made earlier about thinking strategically about Board membership and being clear about what is expected of partners.

Sufficient resources are also necessary to let the “community” know your project is out there. Advertisement, either by print, radio, or billboards, is important in raising the project’s visibility and the community’s awareness of the project.

**7. Devise a pilot-testing phase with a “step-out” clause.**

For very good reason, ZAP Asthma tried to avoid using the term “pilot project.” The community made it clear it had been afflicted with too many pilot projects in the past that made grandiose promises and then left once the demonstration funds ran out. Hence, ZAP Asthma wanted to convey from the start a long-term commitment to the community. However, because the venture was a new one for many of the partners and because the goals of ZAP Asthma were varied and complex, some partners, in retrospect, would have preferred a “probationary” period after which the situation and their roles and responsibilities could be reassessed and a more informed determination to move forward made. Failure to do this, although it may have avoided offending the community, resulted in partners who could not and did not keep commitments because they either did not fully understand the commitments at the start, or because the commitments evolved with the need of the project.

**8. Be strategic about Board composition.**

The partners at the table must reflect the full array of needs of the project. All the more reason that there must be consensus up front about the vision. In the end, ZAP Asthma was constrained because of key gaps in the consortium, including public relations (PR) and marketing, fundraising, outreach to community institutions and even something as simple as mattress manufacturers. In particular, the lack of PR and marketing expertise on the Board and ZAP’s inability to purchase it in the community hindered their ability to achieve the critical mass of publicity that might have helped ZAP engage the multiple layers of the community.

**9. Get commitments from stakeholder organizations, not just stakeholder personalities.**

Committed individuals are of little utility to a complex effort like ZAP Asthma unless they speak for, can mobilize, and make commitments on behalf of their organizations. While the expertise of individuals is important, ZAP Asthma-like efforts are about mobilizing resources, and that means engaging organizations. In addition, a partnership of committed organizations is less likely to fall prey, as ZAP Asthma did in its early years, to lengthy transitions when personalities change.

**10. Skew decision-making processes towards inclusiveness and multiple channels of communication.**

ZAP Asthma is a complex initiative operating in a complex larger environment. Lessons from organization theory tell us that in complex environments, inclusive decision making and open and multiple channels of communication are key to timely and effective response to changes in the environment. Front-line staff are often the first to feel these changes in the environment. ZAP Asthma learned over time how to create ways to incorporate this “field intelligence” into Board decision-making. Likewise, as in ZAP Asthma’s case, Executive Committees play a larger role where in decisions must be made rapidly to respond to a turbulent environment. But it is essential to create ways for decisions to be communicated to the rest of the Board so that they retain some sense of common ownership.

**11. View front-line staff as representing a “pool of expertise.”**

In recruiting CHWs, skills should match role specialization. Successfully organizing and implementing community-based health education programs requires a different skill set than conducting one-on-one in-home health education and counseling. Even with training, not all persons are equally suited to doing community organizing and presenting information in large-group settings.

**12. This can work!!!**

Despite the obstacles encountered by ZAP Asthma, respondents frequently stated that what they or their organization learned as a result of participating in ZAP Asthma is that a project of this magnitude and complexity can be done. People with varied interests and backgrounds can come together to work collaboratively on an issue of importance and, hopefully, make a difference.

### I. Background and History

ZAP Asthma is a complex public-private partnership in Atlanta focused on reducing the incidence of negative health outcomes associated with pediatric asthma. ZAP Asthma's goal is to demonstrate the effectiveness of environmental control and health education strategies to decrease asthma morbidity and mortality in the Atlanta Empowerment Zone. A key component of these efforts, particularly the health education strategies, lies in community engagement. The initiative presumes that extensive collaboration between low-income communities most affected by pediatric asthma, (health care providers, and public health decision makers and researchers) will produce improvements in health that none of the partners could hope to achieve working independently.

A consortium of 18 partners, including the Rollins School of Public Health at Emory University in Atlanta, the Atlanta Empowerment Zone Corporation and the related Community Empowerment Advisory Board, the Centers for Disease Control and Prevention, the American Association of Health Plans, six area managed care organizations, the American Lung Association of Georgia, the Environmental Justice Center of Clark Atlanta University, Southwest Hospital and Medical Center, and public safety net providers (e.g., Fulton County Health Department and Grady Health Systems), participated in varying degrees in the initial conception of the ZAP Asthma Project in 1995 and its subsequent evolution. The project officially began operation as ZAP Asthma when bylaws were signed in January 1997.

Representatives from these 18 different organizations have come together to create a collaborative partnership that also serves as the governance structure, also known as the Board of Directors, for ZAP Asthma. This governance structure is responsible for making policy and, to a lesser extent, operational decisions for ZAP. The board meets in person on a quarterly basis. In order to minimize the possibility that those partners who control the purse strings would have an inordinate amount of influence in policy and operational decisions, a separate 501(c)(3) was established to manage fiduciary responsibilities.

The management of day-to-day activities falls under the purview of the Executive Office, which currently consists of two CDC-funded staff who function as program managers and divide the responsibilities previously managed by one of the founders of the ZAP initiative until his untimely death. The Executive Office is primarily responsible for managing the following five functional areas:

- Health education, health promotion, health communication and public affairs
- Clinical interventions
- Prevention interventions
- Evaluation
- Community development and training

In addition to their governance responsibilities, partner organizations contributed expertise and financial and in-kind resources to the aforementioned functional areas.

Another important component of the governance structure is the Executive Committee which provides oversight to the Executive Office and functions as a liaison between the Executive Office and the Board. Usually, issues that arise are first brought before the Executive Committee for consideration and recommended course of action and then presented to the board to vote upon. Although a core group of partners, including the CDC and one representative from the HMOs participate on the Executive Committee, meetings are open to all interested partners.

## **The Science Protocol**

At the heart of ZAP Asthma is a research study that was designed to test the effectiveness of controlling environmental triggers, such as dust mites and cockroaches, in improving health status and decreasing the morbidity and financial costs associated with pediatric asthma in the Atlanta Empowerment Zone. Central to the research design is a group of Community Health Workers (CHWs) who are community residents trained by ZAP Asthma to go into families' homes to deliver an intervention consisting of roach eradication, professional house cleaning, and encasing bedding and pillows as well as health education messages and referrals, including smoking cessation when necessary.

CHWs are also responsible for recruiting children from the emergency room, and for in-home data collection, such as administering surveys and collecting dust samples in addition to their expanded duties of outreach and health education for the larger community. In addition to the research protocol and the outcomes with targeted families, ZAP Asthma intended to engage and educate the community at large. CHWs became a critical link in ZAP Asthma's efforts to engage the community as partners in the ZAP Asthma consortium and deliver asthma-related health communication and education activities in the community.

The protocol originally had the goal of enrolling 400 children with asthma between the ages of 5 and 12 who live in the Atlanta Empowerment Zone, Southwest Atlanta corridor, and linkage communities; and who are not involved in other asthma studies. This target number, based on results from similar environmental control studies, was thought to be a feasible and realistic sample size to detect any changes that may be due to the protocol. Initially, the 400 children were to be randomized into two groups of 200 children each. The first group was to receive the environmental interventions in the home under the supervision of the CHWs. The second group of children was to serve as controls for the first group; however, they would be eligible to receive the same interventions 22 months after enrollment of the first group. This design was to ethically ensure that both groups benefit from the gains of the intervention, if it was proven to be successful. These potential gains included increased access to health care through coordination of care between ER and providers, knowledge and use of asthma management guidelines, roach eradication, professional housecleaning and continual monitoring of allergen levels in the home through periodic environmental dust samples.



Initially, the research protocol was to be implemented in four phases, over six years. In the first phase, ZAP Asthma would engage the community, recruit community health workers (CHWs), and pilot the protocols and instruments. In the second phase, ZAP Asthma would undertake a feasibility evaluation. Full implementation would occur in the third phase, and construction of the database, analysis, and evaluation would occur in the fourth and final phase. At the time of this evaluation, ZAP Asthma was in the midst of the third phase, although the phase two feasibility had been confined primarily to review of the partnership.

In order to determine the success of the environmental protocol, several outcome measures have been tracked and currently are being evaluated by the scientists in charge of the research protocol. These measures fall into the following clusters:

- ❑ Environmental
  - Ambient levels of allergens
  - Concentration of allergens and dust samples (cockroach, cat, dog, tree, grass, and fungi)
  - Blood cotinine levels
- ❑ Morbidity
  - ER visits
  - Hospitalizations
  - Non-ER clinic visits
- ❑ Health status
  - Peak flow
  - Medication utilization
  - Asthma severity scores
  - Hospital visits
- ❑ Prevention effectiveness/economic analysis
  - Lost school days
  - Lost workdays by caregiver
- ❑ Process
  - Increased knowledge about asthma
  - Improved home environment
  - Improved access to care

Several changes have occurred to the research protocol over the life of the project. Most significantly, in August 1999, in response to lower-than-expected recruitment and retention numbers, a decision was made to convert the wait-listed control group into an experimental group. As a result, the study would now utilize a pre-post test design instead of the more rigorous individual randomized control study. This pre-post test design was projected to reduce the number of families required to perform a valid and reliable analysis from 400 to 120. In February 2000, when it became apparent that even these numbers would not be reached, the Institutional Review Board at the CDC withdrew its approval for the study. Although analysis of data collected on previously enrolled families continues, data collection has been terminated.

In September 1998, CDC commissioned ORC Macro to conduct an evaluation of aspects of ZAP Asthma. Of the many aspects of ZAP Asthma worthy of evaluation, the ORC Macro evaluation was to focus on the evolution of the partnership and the CHW role. In particular, the study questions included:

- ❑ Evolution of the consortium
  - (How) did disparate organizational “players” become an active inter-organizational collaborative?
  - (How) did the inter-organizational collaborative engage and interact with the community in an effective way?
  - (How) did the collaborative approach lead to community empowerment?
  - (How) did the collaborative approach lead to system improvement and capacity building at the community level?
  
- ❑ Evolution of the CHW role
  - What role did CHWs play?
  - (How) did use of CHWs contribute to project participants learning more about their child’s disease and gaining self-management skills?

## II. Methods

At the start of the project, ORC Macro staff reviewed documents from prior studies of ZAP Asthma and internal documents. These included focus groups sponsored by independent organizations such as the Soap and Detergent Association and the Center for Health Systems Research and Analysis and notes from a facilitated strategic planning retreat held in November 1997. In addition, ORC Macro staff held discussions with other evaluators and researchers who were planning to study other components or processes. These included researchers at Emory University who are evaluating the cost-effectiveness of the initiative and researchers at the School of Social Work, Clark Atlanta University, who are utilizing “results mapping” methodology to document and capture best practices and other intended and unintended consequences of the initiative on the family, the community and the CHWs.

Of most relevance to the ORC Macro evaluation is a study by Research Triangle Institute (RTI) entitled the *Evaluation of the Asthma Initiative Partnership Development*.<sup>1</sup> The report focused on the development of the consortium and was based on interviews, document review, and observation with members of the collaborative conducted during late 1996. At the time of the evaluation, the consortium members had developed a “vision” and articulated values, were operating under a formal governance and organization structure, and had completed board membership and a stakeholder map.

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<sup>1</sup> Griffith, JD, and Lux, L. *Evaluation of the Asthma Initiative Partnership Development*. Research Triangle Institute, January 1997.

Early in the project and based on the review of the RTI report and other findings, ORC Macro staff conducted in-person and telephone interviews with 25 ZAP Asthma board members, staff members, and community representatives. These interviews lasted approximately 45-60 minutes and were intended to obtain a more complete understanding of ZAP Asthma's goals, history, and implementation challenges. These initial interviews also allowed ORC Macro staff to better understand what was expected from the evaluation and clarify any misperceptions about the focus of the evaluation. A copy of the initial interview instrument is included in [Appendix A](#). Key questions in these interviews:

- ❑ What is your role in the consortium?
- ❑ How would you describe the purpose of ZAP Asthma?
- ❑ Are there fissure/tensions/factions in the group? If so, can you briefly discuss them?
- ❑ What do you think the evaluation will show at this point in the life of the project?
- ❑ What is unique about the ZAP Asthma approach that needs to be captured in the evaluation?
- ❑ What do you think the evaluation should focus on?

A logic model was developed based on these document reviews and interviews and presented to the Executive Committee. The logic model is a graphical representation of the relationship between the different components of ZAP Asthma and the expected short-, intermediate-, and long-term outcomes. It focused the discussion with the Executive Committee on the emphasis of the evaluation and the key study questions. A copy of this logic model is in [Appendix B](#). The logic model also helped determine the most appropriate data collection methods for the study. These methods included the following:

## **1. Followup Research with Partners, Staff and Community Members**

One-on-one, telephone interviews with partners; CHWs and community members interviews were conducted approximately 9 months after the initial interviews. The questions, a more in-depth exploration of the workings of the collaborative partnership, the role of CHWs, and the future of ZAP Asthma were formalized into 39 Likert scale items and a series of open-ended questions. The Likert scale items focused primarily on questions related to the partnership such as:

- ❑ Inter-organizational aspects of the collaborative. Did the collaborative develop a sense of shared vision, mission, power and decision-making?
- ❑ Intra-organizational aspects of the collaborative. Were relationships among Board and staff effective, appropriate and productive? Were decisions made in a timely and effective manner?
- ❑ Community involvement. Did ZAP Asthma effectively involve different levels of the community?
- ❑ Community legacy. Did ZAP Asthma effectively build capacity in the community and a sense of community empowerment?

In addition, the six open-ended questions asked:

- ❑ (How) did ZAP Asthma change service delivery orientation?
- ❑ (How) did ZAP Asthma respond to challenges?
- ❑ To be more successful, what did ZAP Asthma need in terms of skills, resources and stakeholders?
- ❑ What did partners learn from their participation?
- ❑ Is there a future, beyond the current project, for the consortium and for the CHWs?
- ❑ What criteria would partners use to determine their potential involvement next time?

These followup interviews were conducted in early Fall 1999 with 11 partners and 11 staff members. In addition, shorter versions were conducted with six individuals in the community who were familiar with ZAP but not considered to be partners. These individuals are referred to as community contacts. A copy of the followup interview instrument is included in [Appendix C](#).

## **2. CHW Qualitative Research**

In order to properly evaluate the role of CHWs and their effectiveness as an alternative health service delivery model, it was decided that separate data collection methods were needed to fully capture the CHW experience and the complexity of their contribution to and relationship to the collaborative. The primary methods employed were participant observation, individual interviews and record review. Data collection occurred between June and October 1999.

Participant observation focused on attending weekly case-conferences and staff meetings. Each meeting lasted from 60-90 minutes. These meetings provided an ample opportunity to take notes, and observe staff and supervisor interacting in a natural way. Attendance at these meetings resulted in a verbatim record of the issues that community health workers and ZAP managers discussed about community health worker roles and responsibilities. These observations contributed to understanding of what community health workers were trying to accomplish and the attitudes and feelings they expressed toward their work, in particular, meeting the objectives established by the ZAP research protocol.

The investigator also conducted participant observation at an all-day asthma camp organized and staffed by community health workers held in August 1999. During this camp, the investigator participated in health education workshops held for parents of children with asthma. Attending this asthma camp, allowed the investigator to witness the skills of community health workers in imparting knowledge about asthma and its environmental and clinical management, and to observe the reactions of concerned parents and guardians to community health workers' health communications.

Individual interviews, which lasted from 45-60 minutes, focused on eliciting from community health workers examples of successful interventions and how their work contributed to the quality of life in study households. These interviews were tape-recorded, transcribed and content analyzed.

Finally, we reviewed and abstracted three records for each active community health worker or 24 records. The community health workers' supervisor chose records that at the request of the investigator would provide a detailed picture of how community health workers' contributed to client assessment and disease management. Special attention was paid to reviewing the link between findings of environmental assessments (i.e., baseline and followup Health and Environmental Surveys) and progress notes arising from community health worker intervention visits. The complete findings of this research are included in a separate report that serves as a technical supplement to this final report.<sup>2</sup>

### 3. Focus Groups

Focus groups were conducted with parents of children who were once enrolled in the intervention and with stakeholders, mainly community-based physicians and HMO representatives, who may be interested in continuing or incorporating aspects of ZAP into the way they deliver services. The purpose of the family focus group, conducted in December 1999 with 8 parents, was to gain insight into what the reasons and barriers were to the families continuing to participate as study subjects and what can be done to improve both recruitment and retention. A copy of the focus group protocol is included in [Appendix D](#). Key questions included:

- ❑ Knowledge of asthma, its triggers and chronic nature
- ❑ Knowledge and understanding of ZAP Asthma
- ❑ Relationship with CHWs
- ❑ Reasons for discontinuing relationship with the project

The protocol for the two stakeholder focus groups held in February 1999 focused on the utility of the ZAP Asthma model of community partnership and the ways in which a CHW approach might add value to efforts of the provider. A copy of the focus group protocol is included in [Appendix E](#).

## III. Findings

This section integrates the findings from all data collection activities and are organized into the following six categories:

- ❑ ZAP Asthma's intended objectives
- ❑ Inter-organizational collaboration
- ❑ Intra-organizational collaboration
- ❑ Community empowerment and capacity building
- ❑ Role of the CHWs
- ❑ The Future of ZAP Asthma

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<sup>2</sup> Friedlob, A. Use of community health workers in ZAP Asthma: Observations and lessons learned. Citizen Science. May 5, 2000.

## A. ZAP Asthma's Objectives and Purpose

Several characteristics of ZAP Asthma make it a unique project and influence both attempts to evaluate the project and the types of evaluation results found. First, ZAP Asthma is a multi-faceted intervention with multiple layers of goals that often compete with one another. ZAP Asthma staff often present the project as a VIN diagram depicting three interrelated circles. The center circle encompasses the scientific protocol and lies at the heart of ZAP Asthma. The second circle represents the health education and promotion efforts targeted both to families involved in the protocol and the larger community. The third circle is where the partners and community come together to work collaboratively on improving the lives of children with asthma. It is at this level where public and private healthcare systems become interconnected and, as a result, change should occur in the ways partners individually and collectively manage and treat disease.

The Community Health Worker (CHW) is envisioned as the critical link among the circles. Their roles and responsibilities change as they move between the circles. The CHWs deliver the intervention to families and act as a link between families and ZAP Asthma. They bring resources from the project to families, but most importantly, they bring the reality of the lives of families and the community to the protocol and the partnership. Many of the implementation challenges encountered by ZAP Asthma can be ascribed to stakeholders' different understandings of the importance of each layer of goals and lack of a clearly articulated connection between the layers.

In the early years of ZAP Asthma, two fissures among stakeholder understandings of the project were a source of conflict, and continued to be to a greater or lesser extent throughout the project. First, while the ZAP Asthma mission statement as listed in publications and formal pronouncements (see text box) included the term “demonstrating the effectiveness of . . .,” partners did not agree on the level of rigor to which the science protocol should adhere, particularly if a very rigorous science protocol was likely to drain resources from all other aspects of the project. While partners often termed this fissure the “science-service” split, the positions were not that clearly drawn, since many who wanted ZAP Asthma to provide service to the community also understood the need for a research protocol.

### ZAP Asthma Mission

*“to demonstrate the effectiveness of environmental control and health education strategies to decrease asthma morbidity and mortality in the Atlanta Empowerment Zone through community engagement”*

The second difference of opinion was over the relative importance of each layer of goals. Although ZAP Asthma's mission statement is broad enough to encompass all three layers<sup>3</sup>, at an operational level, partners had different opinions about the relative emphasis to give to each layer of goals. For some partners, ZAP Asthma's purpose is to address childhood asthma and, thus, the research protocol and the work with families is paramount. For other partners, asthma, while important in its own right, serves as a “platform” for building relationships among the community and institutions. These relationships, these partners hoped, would outlive the asthma initiative and serve as a template for addressing other issues. This “legacy” of ZAP Asthma, while not agreed upon by all stakeholders as a goal, was strongly believed to be by some the primary purpose of ZAP Asthma. In this scenario, ZAP Asthma would present opportunities for and, thus, leave a network of relationships between:

<sup>3</sup> This definition was included in the notes from the planning retreat of November 1997.

- ❑ community and institutions/stakeholders
- ❑ institutions/stakeholders and the community
- ❑ institutions/stakeholders and each other

This multi-layered nature of ZAP Asthma’s goals was apparent early on in the project. The RTI report identified the following project principles for ZAP Asthma:

- ❑ to enhance asthma care for all program children, including maintaining compliance and advice for emergency treatment
- ❑ to increase the knowledge of parents and families about the impact of known factors for asthma exacerbation and improve their ability to self-manage the disease
- ❑ to reduce barriers to the implementation of prevention strategies and access to primary care and the continuity of health services
- ❑ to develop health worker education and training programs for community residents through the use of publicly and privately sponsored disease prevention and health promotion initiatives
- ❑ to build strategic alliances among community-based organizations (public, private, and non-profit) in order to improve the health of citizens of the Atlanta Empowerment Zone and neighboring communities
- ❑ to improve the coordination and continuity of care by enhancing community-based prevention practices and disease management within these communities
- ❑ to design a community-based prevention model that leads to the development and implementation of policies that promote public health<sup>4</sup>

Indeed, in these early formulations, the health education and community legacy goals assume equal if not more prominence than the research protocol. Other key features of the partnership at this time:

- ❑ intended to be full, collaborative relatively among members
- ❑ governance principle gives equal vote to each partner organization
- ❑ public-private partnership
- ❑ not led by a single organization
- ❑ active and continuing community involvement
- ❑ involves partners with very different perspectives, expectations and organizational and professional cultures
- ❑ development has been undertaken at the local level
- ❑ designed to be model for other settings

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<sup>4</sup> Griffith, JD, and Lux, L. *Evaluation of the Asthma Initiative Partnership Development*. Research Triangle Institute, January 1997, pg 1-4.

The major objectives and criteria for success, as outlined in the RTI report, also emphasized the “legacy” aspects of ZAP Asthma as much or more than the outcomes for families:

- ❑ the consortium successfully develops and carries out the initiative in the empowerment zone
- ❑ the partners’ needs are met, and, overall, the partners’ gains from participation make them better off in the partnership than they would be outside it (so they maintain their involvement)
- ❑ the consortium expands into other areas of collaboration
- ❑ the consortium provides a model that is used in other applications or settings<sup>5</sup>

However, by the time of the initial interviews with staff, the goals and objectives of the research protocol had assumed primacy. By this time, the primary and secondary objectives of ZAP Asthma were defined by respondents as:

### **Primary**

- ❑ to decrease the exposure of children with asthma to known environmental risk factors for asthma exacerbation as measured by a decrease in the level of major indoor environmental triggers
- ❑ to decrease morbidity in children with asthma as measured by decreased severity and duration of asthma symptoms
- ❑ to evaluate the effectiveness of the community-based health education and asthma intervention program in improving the quality of life of children with asthma
- ❑ to evaluate the cost-effectiveness of the community-based health education and asthma intervention program
- ❑ to increase the community’s knowledge about the self-management of asthma as measured by improved compliance, increased use of outpatient services, and increased use of community-based health services
- ❑ to identify barriers and facilitators to the development of the partnership which will help refine the model for use in other settings
- ❑ to evaluate the outcomes attributable to the use of a collaborative model to address public health problems

### **Secondary**

- ❑ to evaluate the effectiveness of community-based health education and asthma prevention programs in reducing the use of health care services as measured by a decrease in emergency room visits and hospital admissions for asthma

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<sup>5</sup> Griffith, JD, and Lux, L. *Evaluation of the Asthma Initiative Partnership Development*. Research Triangle Institute, January 1997, pg 15.



- to evaluate the effectiveness of community-based health worker education and training programs in asthma prevention and health promotion

Several factors seem responsible for this evolution in focus of ZAP Asthma. First, there was increasing acknowledgment that the project needed tangible results, and the research protocol offered the most hope for that. Second, and as important, turnover in key staff and partner representatives in the early stages meant that the “institutional memory” was diluted. After the untimely death of one of the key program developers and the unexpected departure of a Principal Investigator, the research protocol was reviewed and modified by a succession of Principal Investigators at about the same time that prominence was being given to the research protocol as the core of ZAP Asthma. What resulted was an elegant but complicated research protocol which, by definition, consumed a great deal of time and resources to effectively implement. These developments in conjunction with less than expected financial and in-kind resources to organize and sustain health education activities in the larger community led to a greater emphasis being placed on the protocol to demonstrate the success of the project and the collaborative partnership. The decision to recruit children solely from emergency rooms also limited the participation and potential buy-in of community members who could act as referral sources; thus further curtailing ZAP’s ability to be visible in the larger community and foster a sense of ownership.

## **B. Inter-Organizational Processes**

The evolution of the collaborative and the development of the various organizational processes to govern it have been monitored since the inception of ZAP Asthma. The RTI report identified the following positive developments and remaining challenges for ZAP Asthma even in the early stages of development.

On the positive side, by the time of the RTI report, relationships had been formalized in Memoranda of Agreement, and considerable work had gone into describing the programmatic components elaborating the actual asthma initiative to be implemented in the empowerment zone (called at the time of the AEZ Asthma Initiative). However, it was unclear at that time whether either the memoranda or the initiative would stand the test of implementation, and all agreed these needed to be tested in the implementation phase.

In terms of purpose, the RTI report applauded the broad scope in recognition of the fact that a complicated problem like asthma required multiple approaches. A broad approach was also more likely to encompass broad shared interests and bring multiple partners to the table who can each play an important, yet different, role. Furthermore, a broad vision and understanding of purpose allows the consortium as a whole to be responsive to individual partner interests, thus enhancing their sense of joint ownership and willingness to make a commitment to the project. However, the RTI report warned that pursuing multiple approaches simultaneously was likely to strain scarce resources and result in multiple diffuse efforts. As seen later, competing demands in the context of limited financial and in-kind resources did indeed burden ZAP Asthma.

Although, the RTI report acknowledged the significant work that had been done with limited resources and the substantial time and in-kind resources donated by the partners, it found that resource issues should have been discussed even earlier in the intervention. While all involved apparently acknowledged that implementation would require extensive resources, the report noted

that the prospect of “seed money” from the AAHP that never materialized may have lulled people into a false sense of security about what could be accomplished with the existing resources.

The report also noted some advantages and potential challenges in the way in which ZAP Asthma was organized and governed. For example, the initial working group/subcommittee structure allowed individuals who were really committed to the idea of ZAP to come together and create the “ideal” program without much input or oversight from what they thought their primary funding source to be at the time. As a result, other organizations and individuals were subsequently brought on board only to find out the funds were not committed and the partnership would have to be responsible for raising the capital to sustain the initiative. The report also noted that subcommittees required a greater level of communication to keep all parties informed of activities and decision. Without adequate infrastructure, this level of communication can be demanding and not always as successful as RTI found in the early days of ZAP, especially since ZAP itself, along with its infrastructure, were in the beginning stages.

Another potential source of conflict noted in the RTI report was the need for non-voting partners, such as the CDC, to contribute significant resources in order to effectively implement the project. These partners inability to affect policy and operational decisions through use of their vote might affect their willingness to contribute to the project and sustain involvement.

The initial set of ORC Macro interviews with stakeholders focused extensively on issues regarding the partnership, its evolution, and the processes utilized to keep it functioning. Key findings from this initial set of interviews are summarized below, followed by the results of the followup research conducted approximately nine months later.

**□ Do partners have a shared understanding of purpose?**

Between the RTI report and this first round of interviews, participants’ understanding of ZAP Asthma’s purpose had evolved and become more diverse. In particular, these interviews concluded that the understanding of ZAP Asthma’s purpose was highly dependent upon organizational affiliation. At the time of these interviews, the fissure between “science” and “service delivery” emphases was most vivid. As mentioned earlier, conflicts were arising because partners had different understandings what purpose(s) should take priority and a “we” vs. “they” mentality was noted by many. On the one side were those who stated, “*The project is the protocol.*” While on the other side were those who indicated, “*The project is more than the protocol. Asthma is the opportunity.*” Review of the myriad purposes noted by respondents in this phase shows the lack of consensus, or better, the lack of commitment to multiple layers of goals that was still apparent at this time. Purposes reported by these respondents have been clustered into the layers described previously:

### **Family-oriented**

- ❑ improve the lives of children with asthma
- ❑ increase use of asthma clinics, decrease ER visits
- ❑ educate affected families on the dangers of asthma and its chronic nature
- ❑ test whether controlling environmental triggers is a cost-effective way to manage asthma
- ❑ build consensus on one standard treatment and management of asthma among providers

### **Community education-oriented**

- ❑ raise community awareness of the dangers of asthma and its chronic nature
- ❑ determine if community involvement enhances the potential for health behavior change

### **“Legacy”-oriented**

- ❑ empowerment of the community
- ❑ develop an effective public-private partnership model
- ❑ ensure that the model is transferable to other communities and other health issues
- ❑ employ and empower members of the community in the form of CHWs
- ❑ determine if a public-private partnership is an appropriate and effective vehicle to handle public health issues

And, as discussed earlier, underlying these purposes was some difference of opinion on the degree to which these various layers of outcomes needed to be proven through a rigorous science protocol.

#### **❑ Do partners have a shared interest in outcomes?**

Interestingly, between the time of the RTI report and the first set of interviews, while devotion to the multi-layered nature of ZAP Asthma’s goals was still apparent, almost all partners began to give increasing prominence to the research protocol and to share an interest in a successful outcome for this protocol. These interviews indicated that most partners, by this point, were heavily reliant on a successful outcome for the study protocol, but for their own reasons:

- ❑ HMOs wanted to see if public-private partnership and the use of CHWs is a cost-effective approach to disease management. HMOs would also like to promote one standard of care for asthma management.
- ❑ CDC wanted to prove that controlling environmental triggers is an effective approach for asthma management.
- ❑ Grady (Hughes Spalding) was interested in success of the public-private approach as a way to reduce their costs in light of the emphasis in medical care reimbursement away from the emergency room and towards use of primary care physicians.
- ❑ Georgia Hill (ZAP Asthma office) staff wanted to show that educating and empowering families and the larger community works and is worth the investment.

- AEZ wanted to use CHWs as a model of successful employment of residents in the AEZ.

In addition, some respondents indicated that ZAP Asthma had established a lofty vision and created such vague expectations even before full implementation. Hence, many partners felt committed to affirming the truth of this advance notice.

- **Does the partnership have the ability to meet those shared interests and accomplish the shared purpose?**

At the time of these initial interviews, respondents had doubts about the partnership's ability to pull together in a common direction. The perception was that everyone had a different perspective and felt compelled to defend it, which was inhibiting communication and collaboration. Furthermore, the multiple layers of ZAP Asthma goals left room for these multiple, and sometimes conflicting, perspectives. Perceptions of respective roles and responsibilities also differed. HMOs were perceived by others, and in some cases themselves, as "funding partners" although their actual participation in the project was growing. On the other hand, at the time of these initial interviews, one HMO representative served on the Executive Committee where the majority of decisions are made.

For the CDC, the situation was very different. While active on the Executive Committee, CDC staff served in a consultant capacity and were not able to make and enforce policies or procedures. This limited their ability to provide guidance and supervision to CHWs. This "firewall" between CDC and the CHWs followed the organizational chart, and made sense in the early conceptualizations of the project, when equal attention was to be given to the multi-layers of goals, and CHWs were to be active in the individual and community health education piece in addition to their data collection responsibilities. However, respondents in these interviews were already seeing the relative emphasis shift to the research protocol. In this new scenario, the arm's length relationship between CDC and the CHWs meant that CDC could not be apprized of problems as early as might be desired and guidance and supervision on how to best carry out the research activities was not coming directly from staff who developed the protocol.

The lack of open and honest communication among partners affected the ability of the consortium as a whole to meet the individual and shared interests of its members. And, as will be seen in the next section, it had an impact on intra-organizational processes as well.

The second round of interviews in late 1999 showed some positive changes in inter-organizational relationships. [Table 1](#) presents the results of the Likert scale items on inter-organizational relationships. Respondents indicated their agreement with each item on a 1-5 scale, where "1" was "Strongly Disagree" and "5" was "Strongly Agree." The table presents both the average rating of respondents for each item and also the percentage of respondents who gave the item a rating of "4" or "5," "Agree" or "Strongly Agree," respectively. Because some respondents did not feel competent to give ratings on all items, the tables present both the percent of all respondents and the "valid" percent, the percent of those answering the item. The discussion which follows includes insights from review of the scalar ratings as well as from the discussions with respondents regarding those ratings. While [Table 1](#) presents the overall mean rating for all respondents, a later table ([Table 3](#)) presents those Likert scale items for which differences in ratings of partners and staff were statistically significant.

**Table 1**  
**Likert Scale Items: Inter-Organizational Processes**

#	Item	Mean	Ratings of 4-5	
			%	Valid %
19	Partners committed resources	4.17	59.1%	72.2%
20	Partners met resource commitments	4.03	59.1%	76.5%
2	Shared definition of the problem	3.80	68.2%	68.2%
1	Shared vision	3.64	54.5%	57.1%
18	Problem ID and resolution mechanisms	3.58	45.5%	52.6%
4	Sense of joint ownership	3.56	36.4%	50.0%
8	Policy decision process is inclusive	3.50	45.5%	45.5%
5	Appropriate power distribution regarding policy	3.45	45.5%	52.6%
21	Partners actively participated	3.40	36.4%	40.0%
23	Partners understood each others' roles	3.33	36.4%	38.1%
3	Shared approach to the problem	3.25	36.4%	44.4%
17	Effective communication mechanisms	3.16	31.8%	31.8%
7	Policy decisions are timely	3.06	27.3%	33.3%
22	Partners had unproductive conflicts	1.64	0.0%	0.0%

❑ **Shared vision, definition, approach and ownership**

Between the initial and second round of interviews, partners and staff appeared to continue to move towards consensus that the research protocol had assumed greater importance among the multiple layer. However, staff tended to rate the level of shared vision significantly lower than partners which reflects the impact of the tension between the science and service components of ZAP and the closer proximity of staff to this tension on a continuous basis.<sup>6</sup> Although recognition of the importance of the protocol had increased over the life of the project, respondents continued to perceive there was a lack of a shared approach to the problem of pediatric asthma which persisted. The majority of respondents also attributed this lack of shared approach to the lingering tensions between the scientific protocol and the community health education component of ZAP. For these respondents, they were unwilling to sacrifice that layer in order to make the protocol work.

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<sup>6</sup> The mean for partners was 4.04 vs. 3.00 for staff with a p-value of .017.

Interestingly, this disagreement about the approach did not spill over to how respondents rated the extent to which the ZAP collaborative has a shared vision and definition of the problem. The relatively high agreement on these indicators may be more a reflection of the broad scope of the project as discussed earlier. As a result, it is not until the “rubber hits the road” and the consortium needs to decide which vision, and by extension, which approach to the problem to pursue that conflicts arise.

However, according to respondents, by the time of the second round of interviews, this tension was not perceived as generating unproductive conflicts among partners. This perception may reflect both the timing of these interviews—they came after a period of productive discussion about how to solve the recruitment and retention problem—and a tendency within ZAP, as discussed later, that communication is inhibited for fear of giving “bad” news or because other partners are perceived as unwilling to listen if it is contrary to their ideas. Some partners also suggested the perceptions of low unproductive conflict may be due to the mutual respect for efforts to make a complicated project work. As one respondent stated in the initial interviews in response to the question about tension in the partnership, “[t]hat is the funny thing about this project. Each individual gets along marvelously with each other, but it is the package that [doesn’t always work].”

As mentioned, the majority of respondents noted that there had been improvement in these areas in the last six months, primarily due to the availability of data highlighting the problems with retention and recruitment. With the data, it became harder to deny there was a problem and easier to see where in the process problems were occurring. Consequently, the consortium was forced to recognize issues previously ignored or explained away. The data helped the consortium, particularly the Executive Committee, to pull together and focus its efforts on identifying the most effective way to remedy the problems, thus moving them closer to having a shared approach.

In terms of joint ownership, although overall agreement exists that there was a sense of joint ownership, many respondents stated there is the distinct impression that some partners are more involved than others and also more “equal” than others. They tend to attribute this imbalance in power to the needs dictated by the protocol. For instance, several respondents noted that CDC’s higher level of involvement is directly and appropriately related to their need to be more hands-on because of the scientific protocol. Staff were significantly less likely to state there was a high level of joint ownership among the partners.<sup>7</sup> Most often they pointed to the declining participation of partners at board meetings and the prominence of the Executive Committee in the decision-making process.

Respondents also were asked to rate the extent to which partners committed resources and kept their commitments. Although respondents felt tremendous resources had been committed to the project and that most partners met their commitments, there was the recognition by almost all that more was needed to cover current expenses and sustain the project in the future.

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<sup>7</sup> The mean for partners was 4.00 vs. 3.13 with a p-value of .026.

## □ Distribution of power

Although, there appeared to be a high level of overall agreement that the distribution of power among the partners regarding ZAP Asthma policy and operations was appropriate, staff and partners tended to have very different views, particularly with regards to the policy decision-making process. There was general agreement that the board usually made decisions based on the recommendations of the Executive Committee. For partners this reflected an appropriate distribution of power and an inclusive policy making process. However, staff were more likely to state that individual board members should be more involved in the actual decision-making process and not solely acting on the recommendations from the Executive Committee.<sup>8</sup> Staff were also more likely to state that front-line staff, like CHWs, should have more input in the policy-making process.<sup>9</sup> Partners, on the other hand, were aware of front-line staff's limited role, but felt this was appropriate since policy matters were the responsibility of the Board and not the staff.

In terms of operations, there was a similar split between staff and partner ratings, although not as keen.<sup>10</sup> Partners were more likely to report that their role in operational decisions was appropriate, but their actual knowledge of the level of input front-line staff/CHWs have in operational decisions was usually limited. Most often partners attributed their lack of knowledge to their lack of involvement beyond their participation in quarterly board meetings. Staff were more likely to report that the Board was too involved in operational decisions, but it is unclear from the data if they are actually referring to the Board or the Executive Committee. Nevertheless, according to these respondents, the over-involvement decreased ZAP Asthma's ability to be flexible and quickly respond to problems as they arise. As a result, a significant number of respondents, and more staff than partner respondents, felt that ZAP Asthma did not make operational decisions in a timely manner. As noted later, the recruitment and retention issues that jeopardized the protocol have led to perceived improvement in these areas in the last six months.

## C. Intra-Organizational Processes

While not part of the initial set of study questions for the ORC Macro evaluation, the issue of relationships within ZAP Asthma and between the ZAP Asthma governance structure and the staff loomed large in the first round of interviews as ZAP Asthma began to confront issues of decision making and timeliness.

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<sup>8</sup> The mean for partners was 4.00 vs. 2.69 with a p-value of .025.

<sup>9</sup> The mean for partners was 4.00 vs. 2.78 for staff with a p-value of .004.

<sup>10</sup> The mean for partners was 4.22 vs. 3.25 for staff with a p-value of .018.

❑ **Has the partnership accomplished its stated goals according to schedule or in a timely manner?**

At the time of the interviews, respondents believed ZAP Asthma was behind schedule in several key areas. There was a widespread sentiment among respondents that things were taking a lot longer than necessary. In particular, the initiative had not yet developed its health education and health promotion component, due to a misunderstanding of commitments or missed commitments by some partners. Likewise, procedures and processes were not yet in place to guide interaction between ZAP Asthma and families in the study protocol. For example, the smoking cessation program and materials had not yet been approved, so CHWs were unaware of how to intervene with families with a smoker in the household.

Respondents also indicated that some activities, recruitment and retention in particular, were behind schedule because they were based on unrealistic initial assumptions. The most often cited example is the target number for families to be recruited in the protocol. This target number was based on previous environmental control studies, some of which operated in economically depressed areas as ZAP Asthma did. However, few of these studies were dependent on resources from financially strapped local institutions operating in an equally complex political and social environment like ZAP Asthma was. As a result, a more appropriate basis for comparison should have been used to make projections for recruitment and retention for ZAP Asthma.

Respondents believed other activities and events were behind schedule because the ZAP Asthma consortium did not have a way to hold voting and non-voting members accountable to their initial commitments, especially considering the lack of articulation of clear roles and responsibilities for partners prior to their decision to participate in the project.

❑ **Is the leadership/management structure effective?**

At the time of the interviews, the internal management structure was still evolving. The untimely death of a CDC staff member who had been instrumental in establishing ZAP Asthma and managing the consortium led to a reallocation of responsibilities among the staff at the ZAP Asthma office. In interviews at this time, respondents indicate a lack of clarity about the management structure. The deceased staff member's responsibilities had been divided among two or more staff, and the division of responsibilities was still emerging. Still, no central staff figure was responsible for day-to-day management (e.g., an Executive Director who reports directly to the Board), and some respondents favored such a role, sensing that the partnership was too large and unwieldy to make day-to-day decisions on its own about hiring or operations. As one partner noted at the time, "*The operational aspect of the consortium is the Achilles Heel. It is worse than matrix management.*" A CHW noted, "*There are all these Indian chiefs and very few Indians.*"

Respondents' reluctance about Board/Executive Committee involvement in operations was heightened by a sense that the governance structure was dominated by strong personalities, so decisions were not always arrived at by consensus. The leadership included several individuals described as "visionaries" but, ones who respondents feared, did not understand the financial implications of the vision. According to these respondents, the absence of a



strong Executive Director between the staff and the Board/Executive Committee, left them without an intermediary to turn to who also has decision-making power. Said one, “*The problem with ZAP Asthma is responsibility without authority.*”

❑ **Are there established procedures for making decisions?**

By the time of the first round of interviews, the Executive Committee had assumed a central role in ZAP Asthma. Issues were first considered by the Executive Committee who then made recommendations to the Board. However, respondents revealed mixed feelings about this evolving role. Many noted that decision making by the Board via the Executive Committee was very slow and that it was hard to reach consensus or prioritize needs. Yet, others complained that the Executive Committee was assuming too central a role especially since the Board was often expected to vote on issues at the same meeting that the issue was first introduced. Very little time was left for consideration of issues. The mechanism for handling issues that are raised at Board meetings is similar. The Board usually hands over the issue to the Executive Committee for further discussion and recommendation at the next Board meeting.

Respondents indicated that (outside) political pressure had a bearing on some decisions in the early stages of ZAP. Cited most often was the hiring of the CHWs, which was viewed as premature and influenced by outside political forces.<sup>11</sup> Although no actual services or materials were purchased from a funding partner, one respondent indicated that decisions about materials and vendors were influenced by the desire to patronize a funding partner, rather than to use the best materials or vendor available.

At the time of these interviews, respondents did not see an established process for resolving conflicts. However, they indicated that the governance structure was expected to provide an operational framework and establish bylaws and a system for dispute resolution.

❑ **Does clear and frequent communication occur between partners and line staff?**

At the time of the initial interviews, respondents indicated that no mechanisms were in place for CHWs or a designated representative to communicate directly with the Board or the Executive Committee. The CHW supervisor was not included on the Board, Executive Committee or even in the Subcommittee structure. This inhibited information flow between the front-line staff and the Executive Committee. According to respondents, this proved especially problematic because the Executive Committee took an active role in day-to-day operations and, over time, the research protocol, took on increasing prominence. The protocol had been developed primarily by CDC. The communication structure put several layers of bureaucracy between the authors of the protocol and those who needed to implement it at the front line.

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<sup>11</sup> In particular, a desire by some public officials to show that efforts in the AEZ were leading to employment of community residents.

The absence of formal communication mechanisms might have been surmounted by informal or electronic means. However, respondents indicated that lack of computers and software in the Georgia Hill office, especially lack of e-mail for office staff, inhibited the ability of CHWs to communicate with everyone else. The lack of formal mechanisms and of electronic means put extra burdens on the program staff serving as a liaison between CDC and Georgia Hill who were already feeling overworked.

The lack of communication between staff and the Board/Executive Committee had serious consequences in the development of the initiative. In the absence of hard information, both sides tended to give extra weight to perception and rumor. Program staff, who had not established working relationships with the Board, saw them as “they.” In addition, perceiving that individuals had an investment in predetermined outcomes, program staff sensed that the leadership would be adverse to hearing criticism. As a result, staff tended to be reluctant to share information, which further exacerbated the lack of flow of information.

In this round of interviews, CHWs indicated that they relied on the grapevine for information. *“Once we heard rumors that ZAP would shut down and we asked them about it and they told us not to worry. But we are excluded from things like that . . .”*

By the second round of interviews, some, but not all, of these sentiments had changed. [Table 2](#) presents the results of the Likert scale items related to intra-organizational processes (and [Table 3](#) shows those items with significantly different ratings by staff and partners).

#### ❑ **Inclusive operational decision-making process**

Although respondents felt there was improvement in the inclusiveness of the operational decision-making process by the time of the second round of interviews, there was still a lingering perception that it took too long for the Executive Office and Executive Committee to seriously consider the input of front-line staff like CHWs. Improvement in the process was ascribed to the availability of field data that confirmed the concerns CHWs had long been expressing about recruitment and retention.

#### ❑ **Accountability**

In general, respondents gave high ratings to the accountability of the Board. However, some respondents indicated that the accountability was constrained by the active role of the Executive Committee, although most respondents agreed with and appreciated the Executive Committee’s role in the project. When low ratings of accountability were made, the lack of clear roles and responsibilities was the most often cited reasons. According to these respondents, often it is unclear who should be making a decision; therefore, the decision is delayed or never made.

□ **Communication mechanisms**

Between the initial and second round of interviews some improvement in communication mechanisms had been made. The addition of e-mail and voice mail for the ZAP office staff was pointed to most often as examples. To address recent problems with obtaining a quorum at the quarterly board meetings, procedures were implemented that allowed board members to vote via fax and/or e-mail. Despite these technological advancements, respondents continued to report that different interpersonal communication styles, people’s unwillingness to hear “bad” news, and, to a much lesser extent, personality conflicts still prohibited open and honest communication. The availability of recent data highlighting the problems with the protocol and the active discussion by all sides of that issue, were seen by many as a “breakthrough” for the organization, making it easier to discuss alternatives to current policies and procedures.

**Table 2**  
**Likert Scale Items: Intra-Organizational Processes**

#	Item	Mean	Ratings of 4-5	
			%	Valid %
15	Staff have appropriate role in operational decisions	<b>3.77</b>	50.0%	64.7%
14	Board plays appropriate role in operational decisions	<b>3.75</b>	50.0%	78.6%
11	Operational decision process is inclusive	<b>3.46</b>	27.3%	42.9%
13	Accountable governance structure	<b>3.38</b>	50.0%	55.0%
6	Appropriate power distribution regarding operations	<b>3.36</b>	27.3%	42.9%
10	Operational decisions are timely	<b>3.33</b>	27.3%	40.0%

**Table 3**  
**Likert Scale Items:**  
**Statistically Significant Mean Differences Between Partners & Staff**

Item	Partner Mean	Staff Mean	t score	Significance (p-value)
Build capacity of community leadership to be a partner in an initiative like ZAP Asthma in the future	3.40	2.17	4.29	.002
Policy decisions process is inclusive	4.00	2.78	3.30	.004
Involved community leadership structure	4.00	3.00	3.19	.009
Involved community institutions	3.85	3.00	2.86	.011
Effective communication mechanisms	3.50	2.67	3.65	.015
Shared vision	4.04	3.00	2.62	.017
Front line staff appropriately involved in operations decisions	4.22	3.25	2.65	.018
Appropriate power among partners regarding policy	4.00	2.69	2.46	.025
Shared sense of 'joint ownership'	4.00	3.13	2.50	.026
Involved families in decisions about care of the child	4.50	3.75	2.35	.031
Understood partners roles	3.65	2.81	2.29	.033
Helped families make good decisions about health	4.33	3.67	2.24	.049

#### **D. Community Engagement and Capacity Building**

As mentioned, the emphasis on community engagement and capacity building was stronger in the early days of ZAP Asthma. The RTI report saw the following positive development and challenges in ZAP Asthma’s early effort at community partnership.

The report favorably noted that there had been community support and involvement in development of the ZAP Asthma initiative. Their involvement was mostly in the form of their work with AEZ to help define the focus of ZAP Asthma. The initiative was seen fundamentally as a local initiative, as opposed to one imposed by an outside organization. Finally, in the early days of the initiative, ZAP Asthma helped to foster links between the community and both CDC and the HMOs; exemplary instances of the “legacy” ZAP Asthma had hoped to leave in the community.

At this early date, the RTI report noted that the collaborative needed to pay more attention to the larger community issues as well as to efforts with families. This would entail more time and effort devoted to outreach to the community, encourage more active community participation and more community involvement on the Board of Directors which provides oversight to the policy making activities of ZAP Asthma.

In the first round of interviews, ORC Macro staff explored several dimensions related to community engagement and capacity building.

□ **(How) is community participation encouraged and facilitated?**

Respondents had divergent opinions about the extent of community involvement in the creation and evolution of ZAP Asthma. Some indicated there was extensive interaction with the community in the process of defining asthma as the focal issue and other aspects of development of the initiative. Others indicated that the focus on asthma was decided by the HMOs and some of the ZAP Asthma leadership. At that point, CDC was brought in for technical expertise. Once the focus was decided upon, it was presented to the community for approval. Community (as represented by the AEZ) was originally interested in other topics such as teen pregnancy and violence, but was persuaded those problems would be too difficult for the project to address effectively and within their pre-determined guidelines. While some recall extensive involvement of the community in the review of the protocol, others indicated that community participation was not sought when the protocol was under development for fear the community would demand changes in the protocol development that ZAP Asthma and CDC scientists were unable or unwilling to make.

Whether the community was actively involved in ZAP Asthma also appears to be dependent upon one's definition of community, especially as it relates to the respondent's opinion about the CHWs. Some believed that the involvement of CHWs in the project constituted community involvement since the community helped recruit the CHWs and most were drawn from the community. However, others indicated that since the CHWs were also employees of ZAP Asthma, this did not constitute community involvement. These respondents stated, "*The community is faceless [in ZAP Asthma] with the exception of CHWs.*"

By the second round of interviews, there were several changes in the perception of respondents regarding ZAP Asthma's engagement of the community. [Tables 4](#) and [5](#) present the results of the Likert scale items related to community engagement and capacity building. Some themes in these items and the surrounding discussion are:

**Table 4**  
**Likert Scale Items: Community Engagement**

#	Item	Mean	Ratings of 4-5	
			%	Valid %
30	Involved families in decisions about child	<b>4.18</b>	72.7%	84.2%
25	Visible to community leadership structure	<b>3.85</b>	40.9%	69.2%
29	Involved community institutions	<b>3.55</b>	50.0%	55.0%
28	Involved community leadership structure	<b>3.54</b>	27.3%	46.2%
26	Visible to community institutions	<b>3.43</b>	27.3%	40.0%
24	Visible with average community person	<b>3.36</b>	22.7%	45.5%
27	Involved average community person	<b>3.23</b>	18.2%	30.8%

**Table 5**  
**Likert Scale Items: Community Capacity Building**

#	Item	Mean	Ratings of 4-5	
			%	Valid %
38	Built capacity of providers to interact with the community	<b>3.19</b>	31.8%	43.8%
36	Resulted in health system improvement	<b>3.17</b>	22.7%	33.3%
37	Built capacity of area service providers re: asthma	<b>2.94</b>	18.2%	23.5%
34	Made leadership better able to interact with institutions	<b>2.79</b>	9.1%	16.7%
35	Built capacity of the community leadership to be a partner in an initiative like ZAP Asthma in the future	<b>2.73</b>	9.1%	18.2%
39	Stimulated economic revival	<b>2.50</b>	9.1	28.6%
33	Made residents better able to approach institutions	<b>2.46</b>	9.1%	18.2%

#### □ **ZAP Asthma’s visibility to and involvement of the community**

Perceptions of ZAP Asthma’s visibility to the average community member tends to vary, and the ratings appear to depend upon how familiar the respondent was with the geographical community of ZAP Asthma. These were among the items with the highest percentage of “Don’t Know” responses. Partners were more likely to respond that they were not familiar enough with the community or its residents to accurately gauge the level of ZAP’s visibility. Of those who felt comfortable enough to offer an opinion, there was agreement that ZAP had been successful at reaching out to community leadership, and to a lesser extent, community organizations, especially in the early days of ZAP. Respondents most often pointed to health fairs, day camps, support groups and displays at MARTA stations as tangible examples of ZAP Asthma’s efforts to provide services for and involve community residents, organizations and leadership. However, below the level of community leadership, as [Table 4](#) indicates, respondents rate ZAP Asthma lower on engagement and involvement.

Furthermore, staff rated the involvement of community leadership and institutions significantly lower than did partners.<sup>12</sup> Although they agreed that ZAP attempted to accomplish these goals, particularly in the early days of the project, these efforts waned as the growing importance of the research protocol and limited funds and staff, shifted the emphasis away from building awareness of ZAP Asthma via community based educational and promotional events in the neighborhoods that comprise the AEZ. Respondents felt that these constraints, in conjunction with the awareness of problems related to the protocol, also curtailed ZAP Asthma’s ability to effectively conceptualize, plan and capitalize on the expertise offered by individuals, including community members, who wanted to participate in ZAP Asthma. As a result, several potential opportunities were missed.

#### □ **ZAP Asthma’s efforts to build capacity at the individual, family and community level**

Most respondents either did not know or felt it was too early to tell if ZAP had been successful at helping the average community resident or leader to improve their interactions with community institutions. Indeed, despite the prominence of this “legacy” goal in the early conceptualization of the project, many respondents indicated they were unsure if this was a goal of ZAP Asthma. Where they acknowledged that it was, emphasis on the protocol combined with limited manpower and funds were indicated as the reasons precluding them from focusing efforts in this area. Ratings were similar for the related item, building the community’s capacity to do an initiative like ZAP Asthma in the future. Several respondents commented that this was not a realistic goal for ZAP Asthma since, by definition, ZAP Asthma is a collaborative partnership and the community could never be expected to take the place of, or assume the role of, the consortium.

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<sup>12</sup> Regarding community leadership, the mean for partners was 4.00 vs. 3.00 with a p value of .009. For community institutions it was 3.85 vs 3.00 with a p-value of .011.

At the family level (see [Table 6](#)), respondents were more positive in their estimation of ZAP’s ability to involve families and influence their decision-making related to both asthma and their health care in general. When responding to these items both staff and partners made it clear they were referring to the fact that families had remained in the protocol. For families who left the protocol, ZAP’s influence was less clear (although as discussed later, even families who left the protocol felt lingering influences from their involvement). The success was largely attributed to the relationships CHWs have been able to build with families who remained in the protocol. Although both staff and partners felt that ZAP was successful at this, partners tended to have a more glowing perception than staff.<sup>13</sup> This may be due to the increased level of knowledge of staff about the problems ZAP Asthma was experiencing with the protocol.

**Table 6**  
**Likert Scale Items: Families**

#	Item	Mean	Ratings of 4-5	
			%	Valid %
31	Helped families make good decisions: asthma	<b>4.23</b>	54.5%	92.3%
32	Helped families make good decisions: health	<b>4.00</b>	45.5%	83.3%

□ **ZAP Asthma’s system impacts**

At the time of the second round of interviews, most respondents stated either they did not know or felt it was too early to tell what impact ZAP Asthma has had on health systems, pediatric asthma providers, hospitals or managed care companies. They felt the final results of the research protocol would ultimately determine how the impact is assessed. Of the small group of physicians and hospital staff involved in the protocol, several respondents felt that ZAP Asthma had a positive impact on raising their awareness and affecting the way services are delivered in their practices or institutions; however, it is difficult to tell how lasting those impacts will be given the bureaucracies within the respective institutions. Several other respondents stated that the primary mechanism to reach out to and involve pediatric asthma providers, the Physician Advisory Committee, never really came together. As a result, ZAP did not substantially engage in the planned activities of physician education that may have ultimately led to the adoption of an agreed upon standard of care for pediatric asthma.

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<sup>13</sup> Regarding involvement of families, the mean for partners was 4.50 vs. 3.75 for staff with a p-value of .031. In terms of helping families make good decisions, the mean for partners was 4.33 vs. 3.67 for staff with a p-value of .049.



## E. Indicator Progression

As noted, respondents were asked to disagree or agree on each Likert scale item on a 1-5 scale. In addition, respondents were asked to indicate if the performance of ZAP Asthma on this item had improved, worsened, or stayed the same in the recent past (last six months). [Table 7](#) presents these results. The “best” and “worst” performing indicators are those with the highest and lowest mean ratings by respondents, respectively. We then examined these and identified those which respondents indicated were getting better or getting worse recently. This resulted in a 4-cell table. Due to the nature of the analysis, it is possible for an indicator to have a high mean rating reflecting a change for the better and a high mean rating reflecting a change for the worse. This happened because relatively few respondents stated that indicators were changing either for the better or for the worse. Most respondents said performance had been unchanged. Those that indicated a change had different perceptions about the direction of the change. This was the case, as [Table 7](#) shows, with two indicators –, “shared vision” and a “sense of joint ownership.” In the case of these indicators, these differences in perception of respondents may reflect the respondents differing intimacy with daily workings of the project. Staff were more likely to state that although there was a sense of shared vision and the crisis in the protocol pulled some members of the project closer together, tension still existed between those who felt the service component of ZAP, the community based health education and promotion piece, should receive more attention and prominence within the project. As a result, for some “shared vision” improved while others felt like the emphasis on the research protocol was moving the partnership further away from a “shared vision.” The indicator “sense of joint ownership” experienced a similar phenomenon. Some respondents stated that the crisis in the protocol helped caused them to focus their efforts on sustaining the protocol and thus fostered a common sense of purpose and ownership. However, other respondents felt that the crisis in the protocol focused attention away from the activities they were most concerned about, such as community health education.

**Table 7**  
**Indicators Rated as Getting Better or Worse**

	<b>Change for the Better</b>	<b>Change for the Worse</b>
<b>Best Performance (1)</b>	Shared vision (3) Sense of joint ownership (3) Policy decision process in inclusive Staff have appropriate role in operating decisions Problem ID and resolution mechanisms Involved community leadership structure	Shared vision (3) Sense of joint ownership (3) Partners committed resources Partners met commitments on resources
<b>Worst Performance (2)</b>		Built capacity of area service providers to deal with pediatric asthma

- (1) Best performance refers to those items with average ratings in excess of 3.5
- (2) Worst performance refers to those items with average ratings below 3.0
- (3) Cell entries are those items where the most respondents indicated that in the last 6 months ZAP's performance had changed for the better or the worse. When items show up in both columns, it means clusters of respondents thought performance had changed for the better and others thought it had changed for the worse.

Although several indicators deemed best performers also improved in the last six months, none of the indicators that were worst performers experienced improvement. All of them, with the exception of one, remained the same in the previous six months. That decline of the indicator “built capacity of area service providers to deal with pediatric asthma” was due to the inactivity of the Physicians Advisory Committee, which was developed to provide a forum for physicians in the local community to come together and share their expertise about the treatment of pediatric asthma with ZAP Asthma. In addition, the committee would also offer various educational events for physicians who were interested in learning more about pediatric asthma. The committee was envisioned as a mechanism to build physician support for ZAP Asthma while helping physicians work towards developing a standard of care for pediatric asthma. This did not occur because the committee did not meet often enough to sustain the physician’s involvement. Before the protocol was ended, there were plans to revamp the committee and reach out again to area physicians.

**F. Role of CHWs**

The evaluation included extensive interaction with 10 of the CHWs. ZAP Asthma’s CHWs bring an array of assets to this work. The typical ZAP Asthma CHW is an African-American woman in her forties with roots in both rural Georgia and urban Atlanta. Only one CHW is Caucasian. All CHWs were residents of the AEZ.

Most CHWs were high school graduates who have completed some community college courses without graduating. Most have had some experience in providing human services. Among their prior jobs, CHWs have held jobs as child day care providers; social work assistants for the Department of Family and Children Services; community aides for the local housing authority or the Carter Center's *Atlanta Project*; and as a residential care manager for group homes for seriously mentally ill persons.

A mother or grandmother, most CHWs have been active in school-parent organizations. They also are likely to be involved in neighborhood organizations, block clubs, or community groups, and in church events, including fundraisers. When asked about the things they do best, CHWs expressed a preference for working with people in either a care-taking role, or in organizing, listening to, and supervising people. At the time of the study, CHWs received a wage of \$11.00/hour (approximately \$23,000 per year, plus benefits).

ORC Macro's initial interviews included several items related to the CHWs and their role. These were asked of all respondents, but the initial round of interviews included the incumbent CHW Supervisor and two CHWs. These interviews focused on the following questions:

#### **Are CHWs serving the population they intended to serve?**

At the time of the initial interviews, respondents were concerned that CHWs' ability to serve the target population was being compromised by participants' inability or unwillingness to keep appointments. This was creating a major problem for recruitment and retention in the study because a certain number of appointments and screenings needed to be accomplished for families to progress through the study. Respondents attributed this to several things:

- ❑ Parents' lack of understanding of the chronic nature of asthma. Hence, they continued to deal only with the emergent "crisis." And, per the protocol, the education components of ZAP Asthma do not occur until after the clinic component has been initiated. So, there is little opportunity to correct this misperception in early stages.
- ❑ The requirements of the protocol. Both the frequency and the timing of requirements of the protocol were deemed by the CHWs as too burdensome for families. The lengthy and detailed Health and Environment Survey Instrument (HESI) was often cited as an example.
- ❑ Lack of appropriate incentives. Families were given small incentives – i.e., sample sizes of health and beauty products. The CHWs believed that some sort of incentive – grocery store vouchers or gift certificates – was necessary to engage families, especially in the early stages of the project. However, the ability to use incentives was limited by the requirements (stipulations) of the IRB process.
- ❑ Lack of transportation. Many participating families were dependent on public transportation, which was not always reliable. In addition, because many were in Welfare to Work programs, meeting appointments meant traveling from work to home, school, or day care to pick up the child and then traveling to the clinic.

### **Are CHWs properly trained for their position?**

Several concerns were expressed in the first round of interviews about a potential mismatch between CHW skills and preferences and the requirements of the position. The protocol required “dispassionate” data collection, yet the CHWs wanted to be involved in helping families and actively engaged in the lives of the families. This was exacerbated at the time by perceived lack of training in completing the paperwork related to the protocol and home visits and to relatively frequent changes in the paperwork.

As important, critical supports for the CHWs in their interactions with the families, such as established smoking cessation protocols or programs and health education activities to which families could be referred – were not fully in place. Also, most CHWs, like the families, were dependent on public transportation. This inhibited their ability to be flexible about appointment times, to effectively deal with a geographically far-flung population of families, and to assist with duties like bringing equipment to families’ homes.

### **Do CHWs have an adequate understanding of their job responsibilities? Are they clearly defined?**

CHWs were universally viewed as having some role in recruitment, service delivery, health education and data collection. However, the emphasis among the roles tended to differ by partners. Although a formal job description was developed before recruitment began<sup>14</sup>, several respondents who were involved early on in the project stated they were unaware of its existence. As a result, they were not clear about CHW roles and the relative emphasis that should be given to multiple roles. In particular, those connected with the science protocol tended to see the data collection role as primary. However, this view was not shared by all partners, and was not the preference of the CHWs. At the time of the initial interviews, CHWs indicated dissatisfaction with the emphasis on data collection, and believed it to be a shift from their initial job description. Of particular concern was the length of the HESI, which had not been extensively reviewed before administration in the field. The complexity of the instrument and the time it took to administer it was viewed as burdensome to the families, drove out most other potential “helpful” interactions between the CHWs and the families, and strained the capabilities of the CHWs as data collectors.

A concern of partners and CHWs was that the multiple roles were too demanding and that CHWs could not do all of them well. Those partners with less commitment to the data collection role and more attuned to the long-term “legacy” of ZAP Asthma were concerned that the evolving CHW role would limit the transferability of the model. The utility of the role outside of ZAP Asthma was likely to emphasize the outreach, case management, and health education role. Yet, the evolution of the CHW role was emphasizing data collection to the almost total exclusion of clinical experiences or health education. Accomplishing the multiple roles was also compromised by what the CHWs viewed as inadequate supervision. At the time of the initial interview, the

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<sup>14</sup> The process to develop the job description consisted of a facilitation of a one day “retreat” by a human resources consultant to generate a complete “job design” that would assure that the complex roles would be defined more explicitly. Then, specific competencies were identified that would be needed to carry out the multiple responsibilities. These competencies were used in the recruiting and hiring process. Candidates were then trained using a curriculum based on these identified competencies.

incumbent CHW supervisor was not yet comfortable enough and familiar with the science protocol; therefore, she was unable to serve as a source of adequate supervision to CHWs.

### **Have CHWs personally benefited?**

Because CHWs were intentionally drawn from the community, personal growth and benefit to the CHWs was seen as integral to ZAP Asthma goals related to community empowerment and capacity building. At the time of the initial interviews, respondents believed that some CHWs had benefited personally in several ways:

- ❑ Some CHWs had acquired a work ethic and a sense of professionalism. For several, the CHW position was the first job with significant autonomy and responsibility that they had held. On the other hand, shortly after ORC Macro's initial stakeholder interviews, three CHWs had been terminated because of failure to adhere to work standards.
- ❑ Some CHWs had become home and automobile owners.
- ❑ CHWs reported an increased awareness and understanding of asthma as a chronic disease, which helped them to better manage their own and relatives' asthma.
- ❑ CHWs were learning how to access and utilize community resources, which was seen as an important "spillover" legacy of ZAP Asthma for the community.

While in the second round of data collection there were only a few items in the Likert scale and open-ended questions related to the CHWs, an extensive qualitative research component was devoted exclusively to them. In addition, two sets of focus groups—with families and with providers with potential to adopt/adapt the ZAP Asthma model—addressed the role of the CHWs.

The followup research examined the roles that CHWs were playing. Consistent with the earlier findings, most CHW time was devoted to the ZAP Asthma research protocol. Home visits focused on pest control (i.e., placing baits and gels strategically and educating caregivers on their use); encasing mattresses and pillow covers to control dust mites and educating caregiver on dust and mold control; counseling about the effects of second-hand smoke (if relevant); and distributing health education material.

By the time of the followup research, CHWs were also effectively assuming other duties both with the families and also in the community. In general, these activities appeared to be initiated by the CHWs rather than undertaken in response to ZAP Asthma policies or established approaches. As a result, they tended to be implemented idiosyncratically and were not accompanied by mechanisms to ensure "transfer of knowledge" and identification and routinization of best practices across CHWs. For example, CHWs assisted clients with personal issues such as housing and household needs, but this appeared to be initiated by the CHWs and not as a consistent ZAP Asthma program policy adhered to by all CHWs. In advocating for better housing conditions for her client, one CHW observed: *"I just took it on myself. [I] took pictures of deteriorating housing conditions. [I] found out the owner was going to tear down property...but in the meantime that child needed to be taken care of. We wrote a letter. For legal reasons, we have to do it a certain way... The family moved out of substandard housing. We got them out of there."*

### Who Are the People with Whom the CHWs Are Working?

- ❑ Average age 7.9 years (sd= 2.2)
- ❑ 58% male
- ❑ 98% African-American
- ❑ 59% lived in a multi- unit complex.
- ❑ 30% lived in households with 2 children; 26% 3 children; and 28% 4 or more children.
- ❑ 47% of households included a smoker.
- ❑ 75% did NOT have an asthma management plan at baseline. Of those that did, only 39% could produce it at HESI baseline interview.
- ❑ 59% did NOT have a peak flow meter. Of those that did, two-thirds could produce at HESI baseline visit.
- ❑ 96% of children used prescription asthma medicine.
- ❑ 84% received their care at Hughes-Spalding.
- ❑ CHWs averaged a retention rate of 47.6% (sd=12.8), with ranges from 29.4 to 67.8%\*

\*Using a criterion of a minimum of three program contacts as a definition of a functional asthma disease management program (i.e., baseline environmental assessment, clinic visit and intervention visit or equivalent for Stage II enrollees).

Likewise, CHWs have witnessed and have gained much insight into chronic illness caregiving patterns in children in families where grandparents, siblings, and non-custodial adults play major roles in assuring a child's well-being and quality of life. But, as with the example of housing, this involvement is not framed by ZAP Asthma policies and the resulting insights have not been rigorously documented or shared through case conferences or other reporting mechanisms. While this might be a role played by the CHW Supervisor, communication between CHW supervisors and CHWs tended to emphasize problem identification not problem-solving. CHW supervisors have not generally encouraged teams of CHWs to solve operational problems. Instead, CHWs evolved their own self-managed teams to solve problems. More intentional delegation of authority to CHW teams might have freed the managers to concentrate on coach or trainer roles, working with CHWs to support skill development in assessment, care planning and client communication, while monitoring the quality of CHW interventions.

As in the initial interviews, it was clear that the time demands of the Health Environmental Survey Instrument [HESI] were frustrating to both families and the CHWs. But, the followup research also demonstrated that the baseline HESI was generally underutilized by the CHWs, and the project included no system to do this. In particular, its potential as a source for a household-specific disease management plan was not exploited. Such a plan, based on HESI results, would have included specific actions that the client needed to address in order to control environmental allergens and reduce asthma triggers. Similarly, health education material distributed by the CHWs did not often appear to be customized to, or even related to, the unique findings of the CHWs environmental assessment.

Hence, while CHWs have clearly gained and used assessment skills, inadequate attention is paid to the meaning and utility of these data. In particular, there was need to reinforce the link between assessment and individualized care planning to maximize the potential effectiveness of a CHW in-home intervention. This reinforcement might come from direct supervision, formal in-service training, and regular case-conferences emphasizing how information gained through assessment translates into a plan for health promotion and disease prevention.

Likewise, in their role as health educators/communicators, it is not clear that CHWs have a valid and reliable measure of the severity of a child's asthma after performing their assessment, information that could assist them in targeting the intensity of their health education and environmental interventions.

Likewise, there is virtually no link between clinical care management and environmental interventions. For example, while spirometry results are recorded in the CHWs record (i.e., reports of ZAP Asthma clinic visits are included in the CHW client record), there is no evidence that the CHW or CHW Supervisor, or anyone else, uses these clinical results as feedback. Nor is there evidence that the CHW, or someone else, follows-up with caregivers after ZAP Asthma clinic visits.

CHWs, because they get into the home, were in the best position to observe and reinforce family adherence to clinical care plans, but this role was under utilized. In their home visits, CHWs often observed that peak flow meters are sometimes hidden away. Caregivers also may have asthma management plans, but CHWs would observe instances where they were not adhering to them routinely. Yet, the proper use of a peak flow meter and the importance of having an individualized plan to respond to peak flow meter results; the proper use of spacer in order to deliver medications optimally was not routinely part of ZAP Asthma in-home health education activities. Nor was there evidence in the case files that CHWs encouraged caregivers to request an asthma management plan from the Hughes-Spalding asthma clinic during regular clinic appointments.

Likewise, while both ZAP Asthma partners and CHWs expressed interest in working in the community, both ZAP Asthma recruitment protocols, the competing demands of the CHW role, and missed opportunities meant that much is left to be accomplished in this area. Enrolling children from the emergency room disengaged ZAP Asthma and its CHWs from a neighborhood base. The promise of ZAP Asthma and the use of CHWs was community empowerment around a visible health problem affecting children and families in the target area. Since ZAP Asthma's service area reflects the emergency room's service area, which includes the entire Atlanta metropolitan area, this recruitment model weakened the potential use of CHWs in creating innovative public health strategies that linked asthma disease management to community-building. For example, if clusters of ZAP Asthma children could have been identified, stronger cases might have been made to community merchants, organizations and schools to join together in supporting those families.

Some, but not all, CHWs engaged in the planning and implementing of community health education activities such as asthma summer camps, community-based support groups, or community-based presentations in schools and public housing community centers. Likewise, while some CHWs have expressed interest in developing and implementing asthma education programs in schools, much remains to be accomplished in this area. For example, although the Georgia Lung Association is a ZAP Asthma partner, CHWs have not collaborated with the Association's school-based *Open Airways* program. In general, CHWs did not get involved in these broader community-based initiatives because of the demands of the research protocol.

In short, as in the initial interviews, CHWs yearned to expand their role beyond the research protocol, both in terms of a more comprehensive role with families and a broader role in the

community. To a large extent, this was done by the time of the followup research, however, it was done by individual initiative and competing for time with the demands of the research protocol. CHWs missed opportunities to use their core work in environmental assessment to design individual approaches to families and to use their presence in the home as an opportunity to advance clinical outcomes. Furthermore, CHWs tended to work in isolation from each other. Hence, mechanisms for transferring knowledge and best practices among them did not develop, and interventions with the family outside the confines of the research protocol tended to be ad-hoc. Finally, while some CHWs were involved in community-oriented activities, this was done primarily at their own initiative because of the demands of the research protocol.

## **G. Added Value of CHW Role**

Several data collection components examined the ways in which the CHW model was perceived as adding value to efforts with the family and the community, also the potential for this model in other settings.

The qualitative research with the CHWs found that they possess the knowledge, attitudinal, and behavioral skills to play an influential role in individual health promotion and prevention about managing asthma in children. CHWs had gained experience using health education skills that would make them useful members of an inter-disciplinary asthma disease management team. For example, in addition to planning and implementing environmental interventions, CHWs used knowledge and skills to monitor and reinforce the importance of peak flow plans and medications management.

Furthermore, through ZAP Asthma, CHWs, based on discussions with them, have had the chance to use skills in assessing public health risks in the home environment that may be transferable to other situations. Public health agencies employing CHWs could feasibly expand the scope of practice of a CHW-like staff to include screening for lead paint poisoning risks and the risk of unintentional injury.

However, it was apparent in discussions with the CHWs that, whether with ZAP Asthma or another health issue, they needed to operate as an important component of a team – physicians, nurses, respiratory therapists, social workers and parents. CHWs might have been more effective had a strategic plan been developed for community-based promotions and which linked the work in the home with the larger community outcomes. Instead, because of competing demands on ZAP Asthma, many of these activities would have benefited from a team approach that counted on others to make connections in the community and mobilize other partners. CHWs often identified new opportunities but the implementation involved multiple partners and staff. ZAP Asthma Sundays, day camps and support groups were all activities that included the involvement of HMOs and other volunteers.

While discussions with CHWs during the followup research indicated widespread interest in taking on expanded duties, CHWs ability to take on these expanded functions differed widely, with very few CHWs able to effectively address all these areas. This is not surprising in that the skills to successfully organize and implement community-based health education might differ markedly from those needed to conduct 1:1 in-home health education and counseling. While CHWs can add value to efforts with families and communities, CHWs and partners were clear that CHW duties were unlikely to be filled by a single person. The combination of myriad duties



is likely to require multiple individuals, recruited for their specific skills and acting as a team, rather than a single “general utility” staff member.

A major emphasis of the focus groups with families was on the added value of the CHW role. For families, CHWs were the main face of ZAP Asthma and families uniformly saw the CHWs as adding value and leaving a legacy of increased capability to manage the home environment and their child’s asthma. Several families commented on the crucial role that the CHW played in both explaining the project to them, encouraging them to remain in the program, and accessing other helpful services.

In focus groups of providers, ZAP Asthma’s use of CHWs was mentioned by all participants as having the most potential to positively affect the work the providers do. As residents, CHWs are familiar to families and, therefore, more likely to be trusted as a source of information. As trusted resources, CHWs can gain access to families and be allowed into their homes more easily than other home visitors, such as Visiting Nurse Service , who may be viewed with distrust and suspicion. Families are more comfortable with disclosing private, and sometimes embarrassing, information to CHWs.

In terms of education, CHWs who are residents of the community, are more likely to know how to present the information to make it more easily understood and acceptable to families. They also have the ability to conduct more extensive one-on-one education about disease management as well as detect when there is a disconnect between a person’s stated and actual behavior. As a result, families are more likely to listen and comply with suggested guidelines.

CHWs also assisted with building support for behavior change in the larger community. By spreading the word about the benefits of the ZAP Asthma approach, the community’s awareness of environmental triggers is raised. As they become more knowledgeable of the importance of preventing these triggers, their support for the behavior change grows. This community support makes it easier for residents to adopt and sustain the behavior change necessary to control environmental triggers. As one participant stated, “[c]ommunity support produces sustainability.”

For stakeholders representing community health centers, independently building community support, as evidenced by the active participation of residents such as Mrs. Henderson, was as important as the project’s use of CHWs. In their view, residents’ participation fosters a sense of community empowerment because they are actively working to prevent and control a problem that is taking a large toll on residents’ lives.

CHWs also provided a more effective way to reach people who do not normally present for care or who have limited access to care. By going to their homes, CHWs can help keep them connected to the larger health care system so if a problem does arise, they have a trusted person to turn to. One participant believed CHWs were the advocate or key person to get reluctant individuals “over the hump” and convince them of the value of accessing health care in a timely manner.

One participant envisioned CHWs functioning as “*the foot soldiers of healthcare.*” Under this model, which was asserted by focus group participants from health plans, among others, the role and responsibilities of CHWs would expand to allow them to assess the presence of other health-

related issues in the home and make the appropriate referrals. For example, if a CHW is on a home visit and notices that another family member may be having a health-related problem, that CHW would be able to connect that person with the healthcare system. In this manner, the health care needs of all the individuals in the home are met by the CHW. However, other participants were unsure if CHWs had the training to succeed in this expanded role.

Should the analysis of the data show that the intervention is successful, service delivery organizations adopting the ZAP Asthma model will be able to focus the CHW model on children who would most benefit from the intervention. Because of the randomization process required by the research protocol to test the effectiveness of the intervention, CHWs provided interventions in some home environments where asthma triggers were minimal and the child's clinical signs of asthma were mild, and did not provide interventions in some homes where a child's clinical signs were severe and the home environment evidenced multiple triggers.

## **H. Future of ZAP Asthma**

The open-ended questions asked respondents to reflect on where ZAP Asthma had been and to use this reflection to identify what ZAP Asthma or a similar effort needed to be more effective in the future.

### **□ What did partners learn from their involvement?**

Partners, many of whom had prior experience in the community and with collaborative approaches, were, nonetheless, taken aback at the complexity of ZAP Asthma at all levels.

The lives of the families with which ZAP Asthma worked were more complex than the partners envisioned. Likewise, this complexity resulted in the problem of asthma being interlocked with other issues in the families' lives such as poor housing, lack of transportation and unstable employment. As a result, partners, who expected families to see ZAP Asthma as a positive development in which they would participate gratefully and willingly, realized that ZAP Asthma faced an uphill battle to make asthma a priority in the lives of the families. Incentives were necessary to engage and retain the families, and ZAP Asthma or a similar organization needed to be prepared to take the initiative with families.

Likewise, respondents learned how hard it is to govern a large multi-faceted collaborative. ZAP Asthma brought together science and service components from the public and private sectors. While these were daunting challenges in their own rights, according to respondents with prior experience in collaboratives, ZAP Asthma wanted to be a mechanism for joining these sectors to the community. Defining and engaging the community was more challenging than many partners expected because there are so many layers of the community and so many sub-communities.

Finally, the complexity of the families lives and the governance structure led directly to important lessons about feasible and reasonable expectations of outcomes for an effort like ZAP Asthma. Many partners joined ZAP Asthma expecting tangible health outcomes and, in some cases, cost savings potential for public agencies. While these are reasonable goals, partners now realize that they are long-term ones. The initial stages of a truly collaborative

effort are consumed by the issues of governance and building trust, visibility, and a sense of priority with the community and families. The next ZAP Asthma, partners say, must be sustained by a vision of an improved and empowered community and/or stronger relations among partners and the community, rather than on outcomes.

□ **What is needed to make ZAP Asthma more successful?**

Partners' responses clustered into three categories: skills, resources and stakeholders.

**Skills**

Respondents indicated that ZAP Asthma would have benefited from additional staff or Board expertise in three key and related areas: fundraising, marketing and public relations. Fundraising expertise would have ameliorated the constant sense of fiscal "catch-up." Public relations and marketing would have supported fundraising, by either increasing donations or attracting new partners who could donate time and expertise. In addition, partners and staff saw these skills as needed enhancements to reach goals in community engagement and empowerment.

In addition, ZAP Asthma's complicated governance structure would have benefited from more expertise and training in team approaches to running an organization and in how to implement and routinize participatory management. The Board included committed individuals with limited time to devote to ZAP Asthma. Many activities required melding the resources and expertise of multiple partners into a unified approach. Many respondents saw this as a difficult undertaking that would have benefited from more training and expertise in the organization. Likewise, while the Executive Committee was very involved in operational decisions, the front-line staff were often the first to realize that approaches were not working. Changes in governance structure would have better ensured that front-line experiences made their way into executive decision-making.

**Resources**

Almost all respondents cited financial resources as the thing most needed to make ZAP Asthma more effective. More funding, less restrictive funding, and new Board members who could "open doors" to new sources of funding or other resources were most often cited.

What respondents would do with the additional resources differed little and was closely related to the discussion of skills. Most often, respondents would have devoted the resources to advance the community improvement, engagement, and empowerment goals of ZAP Asthma. Hence, the most common responses were marketing and public relations with the community, health education with the community, and outreach to communities. In addition, respondents saw engagement and retention of families as a key use of more resources, and would devote the money to incentives for families and transportation assistance.

**Stakeholders**

In identifying stakeholders whose participation would enhance ZAP Asthma's success, respondents cited stakeholders from both inside and outside the community. The key stakeholders from outside the community cited by respondents would bring financial

support, bolster a key part of the ZAP Asthma model, or ensure that ZAP Asthma innovations could be routinized into mainstream approaches. For example:

- ❑ Foundations were needed to provide additional financial support for innovative activities.
- ❑ Medical equipment/supplies providers were necessary to help families implement changes in the household.
- ❑ Media connections were seen as vital to provide increased visibility for ZAP Asthma, thus supporting fundraising, attracting additional partners, and helping with goals related to community engagement and empowerment.
- ❑ Representatives from
  - Public officials/policymakers
  - Health department
  - Medicaid
  - Housing Authority

were all seen as essential to ensure the policy changes that were necessary to make ZAP Asthma run smoothly as a demonstration project and to enhance the likelihood that ZAP Asthma's innovative approaches might be mainstreamed. In the case of the housing authority, in particular, a stakeholder on the Board would have lent support to efforts to improve housing conditions for many ZAP Asthma families, whose efforts to reduce environmental triggers were undermined by their deteriorating housing conditions.

Respondents identified key stakeholders from the community as well, whose involvement in ZAP Asthma would enhance its success. For the most part, these reflected earlier findings that ZAP Asthma had effectively engaged the community leadership but needed to do a better job of engaging community organizations and residents. Among those sectors of the community most often cited by respondents were:

- ❑ Community health care providers. While ZAP Asthma may have resulted in considerable learning by providers who were treating ZAP Asthma children, these providers tended not to be from the community. Original goals related to provider education were undone by lack of resources. Community providers on the ZAP Asthma Board might have helped to build those links more effectively.
- ❑ Community businesses. The average merchant in the community was not engaged by ZAP Asthma, but, in the opinion of the respondents, might have played an effective role as donor and also as outlet for community education and outreach.
- ❑ Faith community. Relationships with churches were improving, in the opinion of most respondents, but were late in getting underway, again, because ZAP Asthma was diverted to more immediate fiscal issues. For ZAP Asthma, engagement of the faith community as a stakeholder would offer an important mechanism for outreach to and support of families, as well as partners and a venue for community education.
- ❑ Community-based organizations. A host of voluntary and advocacy organizations operate in ZAP Asthma's catchment area. As with the faith community, more effective engagement would have permitted enhancement of outreach, support and community education.

- Local media. While broadcast media were seen as essential to getting the ZAP Asthma message out to donors and potential partners, local media would bolster community outreach, education and recruitment of families. Active representation on the ZAP Asthma Board might have assisted with identification of the local media channels and best ways to get the ZAP Asthma message to the community.
- Schools. ZAP Asthma made several unsuccessful attempts to engage the local schools. This was unfortunate because the school's offer an obvious support for the child with asthma, education of teachers and coaches is likely to reduce the frequency and severity of attacks, and established links between the school and the parents can aid in education, outreach and recruitment.

□ **What criteria would they use to get involved in something like this again?**

Most responses emphasized the need for more clarity in the beginning so that a well-informed decision about participation could be made. This included more clarity about the responsibilities of each partner up front, not only to ensure that each knew their role, but to ensure that other partners understood and were willing to assume their roles.

In the initial interviews, respondents indicated that costs were not considered during the design of the intervention. "Protocol dictated what we would need and we put the budget together after the protocol." Partners had agreed that funding decisions would be made from year-to-year. While this created a sense of uncertainty, it maintained the funding partners' flexibility and gave them some leverage. Others indicated that all were aware of the lack of resources from the beginning, but participants were unable to decide where to scale back the project. However, by the second round of interviews, most respondents indicated that they would demand some tangible exhibition of commitment (usually funding) early on as a sign that all partners were committed. Moreover, respondents wanted some assurance that partner commitments were sufficient to run the program, or that there were other sources of funding that would ensure sufficient resources.

Some respondents would look at the composition of the Board to ensure that key sectors were part of the project. Even if all partners are committed and willing to contribute, these respondents felt, the project is doomed unless the right stakeholders are engaged.

Finally, some respondents would not participate unless it was clear that partners had similar expectations of the project and that these expectations saw process as important as outcome.

□ **Is there a future for the ZAP Asthma partnership?**

Respondents were almost unanimous that ZAP Asthma as a research project would not outlive the current funding. However, the responses were more mixed for ZAP Asthma as a service project directed at either asthma or a broader vision.

In general, staff responses were less optimistic about the future of the ZAP Asthma consortium than were the partners. In general, they believed that concern about long-term

viability was being addressed too late and with too few resources. As with community empowerment, respondents believed that intentional succession planning needs to be done, and that this effort should have been undertaken earlier.

Respondents believed it needed:

- ❑ a service orientation
- ❑ broader goal than just childhood asthma
- ❑ a central role for the CHWs
- ❑ a smaller scope

❑ **Is there a future for CHWs?**

Most respondents envisioned the CHW function continuing, but were less sure that it would continue under the auspices of ZAP Asthma or any successor agency. More likely, the individual CHWs would be hired by health departments or managed care plans. In either case, respondents believe the new role needs to be more service oriented, and several respondents pointed out the need to better train CHWs to take on these new roles and give them the necessary job-readiness skills that may ultimately determine how transferable the approach is in the long-term.

Respondents were unanimous that the role should be broadened:

- ❑ beyond research
- ❑ beyond an exclusively environmental focus
- ❑ beyond asthma

The utility of the CHW model is in gaining entree and building rapport with the families in a way that may lead to appropriate behavior change. Yet, achieving and maintaining the change means assisting the family in multiple ways. Respondents see the new CHW role as more of a case manager one than a “master environmentalist” one. Likewise, there is utility for the model beyond asthma and potential employers, as exhibited by responses in the focus groups of providers, both the master environmentalist and case manager roles have some appeal to these potential employers.

Respondents cited several potential barriers to sustaining the CHW role. While the CHW model is attractive to managed care plans and health departments, not all respondents are sure that these systems are ready for this model. In addition, while drawing the CHWs from the community may have enhanced their effectiveness with families, who saw them as peers, the skills of the CHWs vary widely, as do their job readiness skills. As one respondent noted, because the CHWs were intentionally drawn from the community, “*they have the same problems as the families.*” In addition, current salaries of CHWs may exceed what this role commands on the open market.

For those respondents who see the CHWs as part of ZAP Asthma’s community empowerment legacy, it is more important that CHWs determine their future, than that the role continue in anything resembling the current role. Said one, “*Sustainability [of CHWs] means they take on leadership, not that they take on the current role.*”

## IV. Integrated Summary by Study Questions

### A. Did disparate organizational “players” become an active *inter-organizational* collaborative?

In general, the Likert scale results show middling-to-good ratings on most indicators related shared vision, mission, and decision-making. While the first round of interviews indicated some concerns in these areas, by the time of the second round of interviews, respondents felt that ZAP Asthma had made considerable progress. While some indicated lingering tension from the early science/service conflict, most saw conditions as improving. Interestingly, many pointed to a crisis as the seminal event that brought the partners closer in terms of unified vision. In summer of 1999, it became apparent that action needed to be taken to ensure that sufficient numbers of families remained in the study to allow the analysis to proceed. In the absence of these numbers, the protocol risked losing IRB approval. This brought issues related to the protocol into prominence, allowed for an airing of issues, and resulted in renewed commitment to the protocol and its success.

Despite the generally positive ratings of the collaborative’s vision and mission, respondents believed that Board member level of commitment and involvement vary widely, and this was seen as detrimental to the project. Likewise, many respondents believe that power is shared unequally, but while this sense is widespread, there is not agreement on which partners have more power.

### B. Did disparate organizational “players” become an active *intra-organizational* collaborative?

Respondents were struck by the complexity of governing a wide-ranging collaborative like ZAP Asthma. And, respondents believe that ZAP Asthma faces challenges in intra-organizational governance. The Board/Executive Committee members are seen as too involved in operations which compromise the ability of staff to be flexible and of operating decisions to be made in a timely fashion. The Board/Executive Committee members are seen as not effectively including staff in decisions, although there was a sense that these mechanisms were improving.

Intra-organizational governance was the area in which staff and partner perceptions varied most significantly, with staff generally painting a more negative picture of these relationships than did partners.

**C. Did the inter-organizational collaborative engage and interact with the community in an effective way?**

Respondents agree that engagement and interaction with the community were constrained by lack of visibility, the result of a lack of resources for marketing and public relations. In general, respondents agreed that ZAP Asthma had done a good job of engaging community *leadership*, especially in the beginning of the project. However, there was less successful engagement of community *organizations* and *residents*, although this was seen as increasing and improving in some cases, such as the faith community. ZAP Asthma was scored even lower by respondents on engagement of the average community resident. CHWs were seen by some as an example of engagement of the community, since they were drawn from the community, but others pointed out that, as employees, it was difficult to see them as examples of engaged community members, although they certainly served as a major channel between ZAP Asthma and the community.

**D. Did the collaborative approach lead to community empowerment?**

“Empowerment” as a term is used broadly and loosely. Here, it is defined as the ability of the community to play a significant role as a partner in a similar endeavor, even if it did not implement the endeavor on its own. Defined in that more limited way, respondents could point to important community-institutional relationships that ZAP Asthma has created and to spillover of ZAP Asthma to self-organizing efforts like support groups and camps. However, most indicated that the “jury was still out” on the degree to which these efforts would live on after ZAP Asthma. In particular, respondents indicated that fiscal and organizational issues diverted ZAP Asthma from the proper succession planning that would be needed to ensure a community legacy.

The CHWs are seen as anxious to carry on aspects of ZAP Asthma’s work, and since the CHWs are drawn from the community and would continue to operate in the community, that is seen by some as evidence of community empowerment.

**E. Did the collaborative approach lead to system improvement and capacity building at the community level?**

While the results of the science protocol have not yet been analyzed, and CHWs’ success in entering the homes has been mixed, most respondents, and the participants in the focus groups of families and providers, saw the CHWs as the main system improvement resulting from ZAP Asthma. However, this presumes and requires that the CHWs are maintained and mainstreamed after ZAP Asthma funding is exhausted.

Other potential system improvements in the community were not realized. In particular, while ZAP Asthma may have influenced health providers, at least in the short-term, few community health providers were among the group of engaged health providers. Again, respondents pointed to missed commitments and lack of resources as the reason why fewer system improvements were realized.



**F. Did use of CHWs contribute to project participants learning more about their child’s disease and gaining self-management skills?**

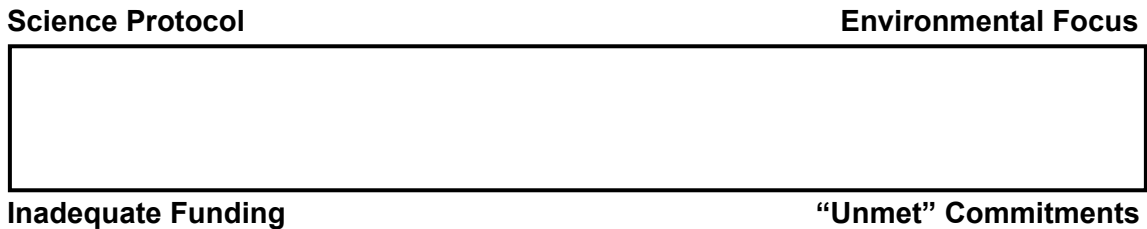
Ultimately, the analysis of data from the science protocol will be necessary to determine the effectiveness of the CHWs. Information from family focus groups indicates that CHWs were seen as adding value to family efforts to learn self-management skills. And provider focus groups clearly indicated interest in the CHW model for a wide variety of illnesses and issues. Also, both staff and partner respondents indicated that ZAP Asthma has made great strides in helping families address their child’s asthma and other health problems.

The qualitative research done with the CHWs was not, by definition, able to address the question of effectiveness directly. However, the research indicated that CHWs were effective at using the skills envisioned by their role. Moreover, CHWs wanted to do more, not less, with families, and believed their ability to help families was constrained by focusing their efforts on the requirements of the science protocol. Indeed, most CHWs stepped outside the role and took on expanded duties. The qualitative research indicated that CHWs *as a group* were effective at both the core and expanded duties.

**V. Conclusions and Lessons**

This section presents underlying patterns visible in the results of the various data collections and also outlines lessons for those seeking to undertake an effort similar to ZAP Asthma.

The obstacles that face ZAP Asthma and constrain its implementation can be represented as an “iron rectangle.” That is, while each factor is an obstacle in its own right, the four factors work together like points on an iron rectangle, reinforcing and constraining each other. One point cannot be moved without changes in the other points, making change particularly difficult. This is especially true given the environment in which the “iron rectangle” is embedded. In the case of ZAP Asthma, the four points on the rectangle are:



The four constraints taken as a group acted in concert such that any solution to one constraint ran up against one or more of the other three. Furthermore, the obstacles that form the iron rectangle were embedded in a complex social environment. The needs of ZAP Asthma’s families and the communities in which they lived were multiple, complicated and interrelated.

- ❑ The **science protocol** and the requirements of the chosen protocol put Community Health Workers into primarily data collection roles. This caused role conflict for them in the face of the multiple needs of the ZAP Asthma families. The chosen protocol also missed potential opportunities to encompass some of the larger community empowerment/capacity building aspects of ZAP Asthma. Although the missed opportunities were attributed to a fissure between science and service, a different protocol that allowed for integration of community and individual goals, might have resulted in a more “united front” by ZAP Asthma stakeholders, and would have resulted in less role conflict by CHWs because the project would be viewed as more comprehensively addressing the needs of families. This role conflict was exacerbated by . . .
  
- ❑ The **environmental focus** which, while justified, caused similar role conflicts for CHWs and staff, because it focused attention on housekeeping and other household behaviors of families without effectively addressing the larger social and economic needs that rendered families unable to adhere to the environmental focus. While this role conflict certainly was exacerbated by the science protocol, it would have existed without it. The population on which ZAP Asthma focused had complicated needs and CHWs, who were drawn from the community and saw themselves in “helping” roles, felt constrained by the narrowness of the environmental focus. The CHWs might have felt less constrained if they saw other activities directed at the broader needs of the families and the community, but . . .
  
- ❑ **Missed/misunderstood commitments** meant that important aspects of the ZAP Asthma model were not implemented as initially envisioned. By default, this put pressure on the ZAP Asthma staff to expand their efforts beyond their main roles to fill in these gaps. Efforts such as community outreach, health education, and provider education were to be led by specific partners or other allies, but were not. While the original intent of ZAP Asthma was to involve ZAP Asthma staff and CHWs in these activities, it certainly was not intended that they do this alone. By default, these activities fell to them in addition to their existing duties. Some of these activities could have been transferred to new staff or outsourced to contractors, but . . .
  
- ❑ **Inadequate funding** meant that ZAP Asthma constantly had to play “catch up” financially to meet even its basic core commitments, diverting its attention from larger community goals and also precluding solutions, such as more staff, that would have eased role conflicts between the science protocol and the larger community legacy.

These four aspects of the project, and the fact they were overlaid on a complicated socio-economic environment, are at the root of most of ZAP Asthma’s challenges. The key to the next ZAP Asthma-like effort is to address these adequately up front. Some lessons include:

**1. Watch out for “fissures” in vision. Do not move forward without a shared vision.**

In this case, the fissure was between the science and the larger community visions of ZAP Asthma. While a research protocol in a community project is uncommon and, perhaps, undoable, there will be other fissures to take its place on the next ZAP Asthma. The lesson from ZAP Asthma is that these must be identified, confronted, and resolved early in the project.

In this case, the fissure was early and deep. The resulting conflicts, tension, and mistrust cost the project perhaps a year and led to independent, almost hermetically sealed, competing versions of what ZAP Asthma was and what was most important. Indeed, to our great surprise, when the evaluation project started, an early task—the development of a logic model—caused several partners to comment that this was the first time they had a full understanding of the larger goals of ZAP Asthma. In retrospect, these differing levels of knowledge and understanding may be due, in part, to the fact that individuals joined and participated in the partnership at varying stages in its conceptualization and implementation.

Part of the fissure was ascribable to the final choice of protocol design. While there was talk initially of a science protocol that would be more open to larger community outcomes, the unfortunate and unavoidable departure of key research staff from the project led to a succession of PI staff with more traditional, and narrower, views of how the science protocol should be implemented. As a result, almost from the start, two competing visions of ZAP Asthma arose. One saw ZAP Asthma as the research protocol. In the best case, this was viewed as an effort to test the effectiveness of an environmental intervention and training of families on the intervention as a method of providing asthma self-management skills in the home. At worst, the requirements reduced the front-line staff role to one of data collection to support the demands of the research protocol. In either case, this vision was much more narrow than its competitor, which viewed ZAP Asthma as an instrument for community engagement, empowerment, and even economic revival. At its most “extreme”, this vision of ZAP Asthma was not about asthma at all, but rather, used asthma as a platform for these larger goals. Key to this vision was leaving a legacy of relationships, capacity, skills, and structure that could be used by ZAP Asthma (as a continuing entity) or by others, preferably from the community, to address other issues. While the learning of families in the home was important in this vision, it was somewhat secondary to more “population-based” orientations such as bringing diverse stakeholders together in a shared vision, and building relationships between community and institutions and among institutions.

While the two visions might have been hard to reconcile under any circumstances, clearly, the final protocol design, and its concomitant processes for recruitment, exacerbated the division. The use of the ER as the recruiting venue, while an effective way to find those with severe asthma, made it hard to link efforts with families to efforts with community institutions such as churches, schools, community-based organizations, and merchants that might have supported the efforts of families. For example, had the protocol had focused on clusters of cases in neighborhoods or schools, it might have more closely aligned the “community vision” activities such as support groups in schools, health fairs, and neighborhood groups, with the intent of the research protocol to train the families of asthmatic children.

The fissure was felt most keenly, but not only, by the front-line staff, who faced competing demands from both the science protocol and the community-oriented, and community legacy aspects of ZAP Asthma. As the science protocol took on increasing prominence, as all realized it held the best hope of tangible findings about success, the front-line staff were thrust into narrower roles than they would have imagined and were promised when first hired. Most either stepped up to the plate and took on expanded duties or felt compelled by others to do so. The absence of additional funds and unmet commitments for health education, provider education and community outreach meant that these too either were undone or fell to the front-line staff.

## **2. Expect complexity.**

In the second round of interviews, when partners were asked to reflect on their experience and what they had learned, most were surprised by the complexity at all levels of the project, including

### **□ Complexity of lives of families**

Families, particularly those in the inner city, often have competing demands that affect their ability to participate at the desired and expected levels in a community-based initiative. Expectations for family participation may need to be adjusted in accordance to these competing demands.

To compete with these various demands, families need incentives to encourage them to participate. However, these incentives do not always need to be financial. For some of the families in ZAP Asthma, gaining knowledge on how to control their child's asthma and the roach eradication were enough. But efforts with many other families would have benefited from additional incentives. The project must be open to considering a wide array of incentives and to using different approaches.

### **□ Complex, interlocking nature of problems in inner-city**

Solving a problem in the inner city usually means first solving several other problems that directly influence or impact the one problem you are trying to solve. Without recognition of the interdependent nature of these problems, insufficient resources will be committed or key partners will be left out of the collaboration. For example, while asthma manifests itself as a health issues, ZAP Asthma addressed root causes in the home. However, families' ability to address the home environment was constrained by the fact they lived in public housing. Hence, a key partner would have been the housing authority.

Likewise, major policy initiatives like Welfare to Work and moving Medicaid-eligible families to managed care models had ripple effects on community-level initiatives like ZAP Asthma. Although the data are anecdotal, staff and partners indicated that Welfare to Work meant that householders were less likely to be at home to keep appointments for house cleaning and inspection and were less likely to have time to wait at clinics for their child's treatment. Unexpected and uncontrollable events can have an impact on the success of an initiative. For instance, welfare reform forced many parents previously expected to be at home into the workforce. This decreased the ability of CHWs to conduct in-home assessments and ultimately affected the number of people who were able to progress in and complete the study.

### **□ Complexity of the governance structure**

ZAP Asthma integrated science and service, public and private sectors, and institutional and community sectors. Defining a governance structure that would be collaborative, yet not result in undue commitments of time for decision-making was a difficult challenge.

Engaging partners is a continuous activity that may take various forms throughout the life of the project. It should not be assumed that because partners are at the table, efforts to engage them are no longer needed. Partners may need guidance in how to make the most effective contribution to the collaborative.

### **3. Define the “community.”**

The definition of “community” includes elected officials, local merchants, civic and religious leaders, schools, hospitals, local physicians, and other professionals. Efforts should be made at the beginning of the project to determine which aspects of the community are most important to the success of the project. Once this determination is made, sufficient resources, including time and manpower, need to be committed to engaging those aspects. ZAP Asthma, as reported by partners, staff, and community contacts, did a good job, especially at the start, of engaging community leaders, but efforts to engage community physicians, community organizations and residents fell prey to fiscal crises.

### **4. Lower Expectations**

Given the complexity of the effort, all partners need to understand that outcomes are long-term and that early stages of the project may result in mainly process improvements. These alone are essential, in that they may be levers to achieve long-term outcomes.

Trust in the knowledge that partners are working toward the same goals and committed to the same outcomes can often be a more powerful motivator than potential cost savings or the outcome itself, especially when cost savings or successful outcome is as apparent as one would like.

Addressing asthma in inner-city populations cannot be divorced from the multiple and complex issues in the lives of those whom ZAP Asthma was trying to serve. Empowering the families and the community to address issues like asthma is a journey with a long-term destination. For ZAP Asthma, expectations by some partners of significant changes in health outcomes of families or even substantial cost savings were naive and unrealistic. Partners must learn to appreciate short-term process goals such building social capital and trusting relationships as useful ends in themselves as well as the necessary “platform” for the desired outcomes.

In collaborations, the focus needs to be shifted away from purely outcomes to one that recognizes the importance of process. The process of building social capital and trusting relationships can be useful in and of itself even if the desired outcome is not achieved. The lessons learned are critical to informing the design and direction of future initiatives. The process may also leave legacies in the community that can be overlooked by focusing solely on outcomes, e.g., Community Health Workers.

Likewise, ZAP would have benefited from more realistic expectations about how to advance knowledge, behavioral intent, and engagement of families. Given the multiple demands on families and the difficulty in getting families to make asthma care a priority, a

“stages of change” approach<sup>15</sup> could have productively been used to build credibility and a relationship between the CHW and the family, and to slowly engage the family more completely in self-management. For example, CHWs indicated that the key activity/intervention that establishes the CHWs credibility is getting rid of roaches. While dust mites may, scientifically, be a more significant contributor to environmental triggers, families cannot see dust mites, but they can see roaches. Accomplishing this goal might establish the credibility necessary to move people further down the road to effective behavioral change to reduce other triggers.

## **5. Roles and responsibilities of partners need to be spelled out up front.**

ZAP Asthma suffered from missed or unmet commitments due in part to a lack of understanding by partners of their role and responsibilities. Because the vision of the project was evolving, so was the role of the partners. In time, for some partners, the roles evolved into something different than their original expectations, leaving some partners unable to meet commitments they may not have realized they had made. Murky understanding of roles and responsibilities had many ripple effects—some partners felt they had to fill in for missed commitments of others. Other partners saw efforts to bolster the project as “power grabs” by other partners. Indeed, most partners saw power among partners as unequal, although none agreed on who had more power.

Discussion about what is expected from individual partners and the collaborative as a whole helps partners make realistic commitments, both tangible and intangible, to the collaborative. It also helps establish trust between the partners when everyone knows and understands his/her own role and the role of others. Partners have more authority to hold each other accountable and can create a system of checks and balances. They also have a greater sense of buy-in to the project when they know what is expected of them. Partners are also more likely to invest resources when they know there is accountability.

## **6. Back up roles and responsibilities with tangible exhibition of commitment up front. Get assurance of enough funds at the start.**

No one thing constrained ZAP Asthma more than the lack of adequate resources up front. All other points on the “iron rectangle” could have been addressed had funds been available to hire staff or bring in expertise to bolster or supplement core staff efforts. Instead, the constant sense of fiscal crisis diverted attention from larger goals to protection of the “vital organs”—the core science protocol and environmental intervention. In ZAP Asthma’s case, the lack of resources is directly related to the points made earlier about thinking strategically about Board membership and being clear about what is expected of partners.

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<sup>15</sup> “Stages of Change”, also known as the Transtheoretical Model, is a theory of health behavior change developed by Jim Prochaska. According to this theory, individuals’ readiness and/or willingness to change their behavior corresponds to six different stages: precontemplation, contemplation, preparation, action, maintenance and termination. In order to influence their level of readiness, health promotion behaviors need to be targeted to correspond to the stage the individual is in. For instance, in precontemplation, individuals are often unaware that there is a problem or have not thought at all about behavior change. As a result, health promotion activities need to focus on raising that person’s level of awareness of the problem and the need for behavior change. “Theory at a Glance: A Guide for Health Promotion Practice” National Institutes of Health, National Cancer Institute.

Sufficient resources are also necessary to let the “community” know your project is out there. Advertisement, either by print, radio, or billboards, is important in raising the project’s visibility and the community’s awareness of the project.

**7. Devise a pilot testing phase with a “step-out” clause.**

For very good reason, ZAP Asthma tried to avoid using the term “pilot project.” The community made clear it had been afflicted with too many pilot projects in the past that made grandiose promises and then left once the demonstration funds ran out. Hence, ZAP Asthma wanted to convey from the start a long-term commitment to the community. However, because the venture was a new one for many of the partners and because the goals of ZAP Asthma were many and complex, some partners, in retrospect, would have preferred a “probationary” period after which the situation and their roles and responsibilities could be reassessed and a more informed determination to move forward made. Failure to do this, although it may have avoided offending the community, resulted in partners who could not and did not keep commitments because they either did not fully understand the commitments at the start, or because the commitments evolved with the need of the project.

**8. Be strategic about Board composition.**

The partners at the table must reflect the full array of needs of the project. All the more reason that there must be consensus up front about the vision. In the end, ZAP Asthma was constrained because of key gaps in the partnership—in public relations (PR) and marketing, in fundraising, outreach to community institutions, and even something as simple as mattress manufacturers.

Were ZAP Asthma’s Board to be reconstituted, key needed expertise would include marketing and PR. ZAP Asthma, because it lacked this expertise on the Board and could not afford to purchase it in the community, was never able to achieve the critical mass of publicity that might have helped ZAP engage the multiple layers of the community.

**9. Get commitments from stakeholder organizations, not just stakeholder personalities.**

Committed individuals are of little utility to a complex effort like ZAP Asthma unless they speak for, can mobilize, and can make commitments on behalf of their organizations. While the expertise of individuals is important, ZAP Asthma-like efforts are about mobilizing resources, and that means engaging organizations. In addition, a partnership of committed organizations is less likely to fall prey, as ZAP Asthma did in its early years, to lengthy transitions when personalities change.

To maximize the contributions of partners, especially in terms of capacity building in distressed communities, partners need to be able to draw upon the resources of the various organizations they are affiliated with. This is easier to do if the organization is as committed to the project as the individual partner. It will also make the collaborative less dependent on personalities who may change through the course of the project.

**10. Skew decision-making processes towards inclusiveness and multiple channels of communication.**

ZAP Asthma is a complex initiative operating in a complex larger environment. Lessons from organization theory tell us that in complex environments, inclusive decision making and open and multiple channels of communication are key to timely and effective response to changes in the environment. Front-line staff are the first to feel the changes in the environment. ZAP Asthma learned over time how to create ways to incorporate this “field intelligence” into Board decision-making. Likewise, as in ZAP Asthma’s case, Executive Committees play a larger role where in decisions must be made rapidly to respond to a turbulent environment. But it is essential to create ways for decisions to be communicated to the rest of the Board so that they retain some sense of common ownership.

Another important element in building trusting relationships is open and honest communication between all parties involved. People need to feel they have a say in order to feel a sense of ownership. They must feel like they are part of the decision-making process, otherwise they will feel little responsibility to commit the time, expertise or financial resources necessary to come up with solutions. To encourage this participation and open communication, multiple methods of communication and soliciting input should be identified.

**11. View front-line staff as representing a “pool of expertise.”**

In recruiting CHWs, skills should match role specialization. Successfully organizing and implementing community-based health education programs requires a different skill set than conducting one-on-one in-home health education and counseling. For example, not all persons are equally suited to doing community organizing and presenting information in large-group settings, even with training.

**12. This can work!!!**

Despite the obstacles encountered by ZAP Asthma, respondents frequently stated that what they or their organization learned as a result of participating in ZAP Asthma is that a project of this magnitude and complexity can be done. People with varied interests and backgrounds can come together to work collaboratively on an issue of importance. Another frequent response was an increased appreciation for how difficult it is to work in low-income inner-city communities, especially in terms of the structural and personal barriers that must be overcome. Respondents were less willing to comment on what others have learned beyond stating that a project like this can be done.



## **Appendix A**

### **Interview Instrument: Initial Interviews**

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**Interview Instrument: Initial Interviews**

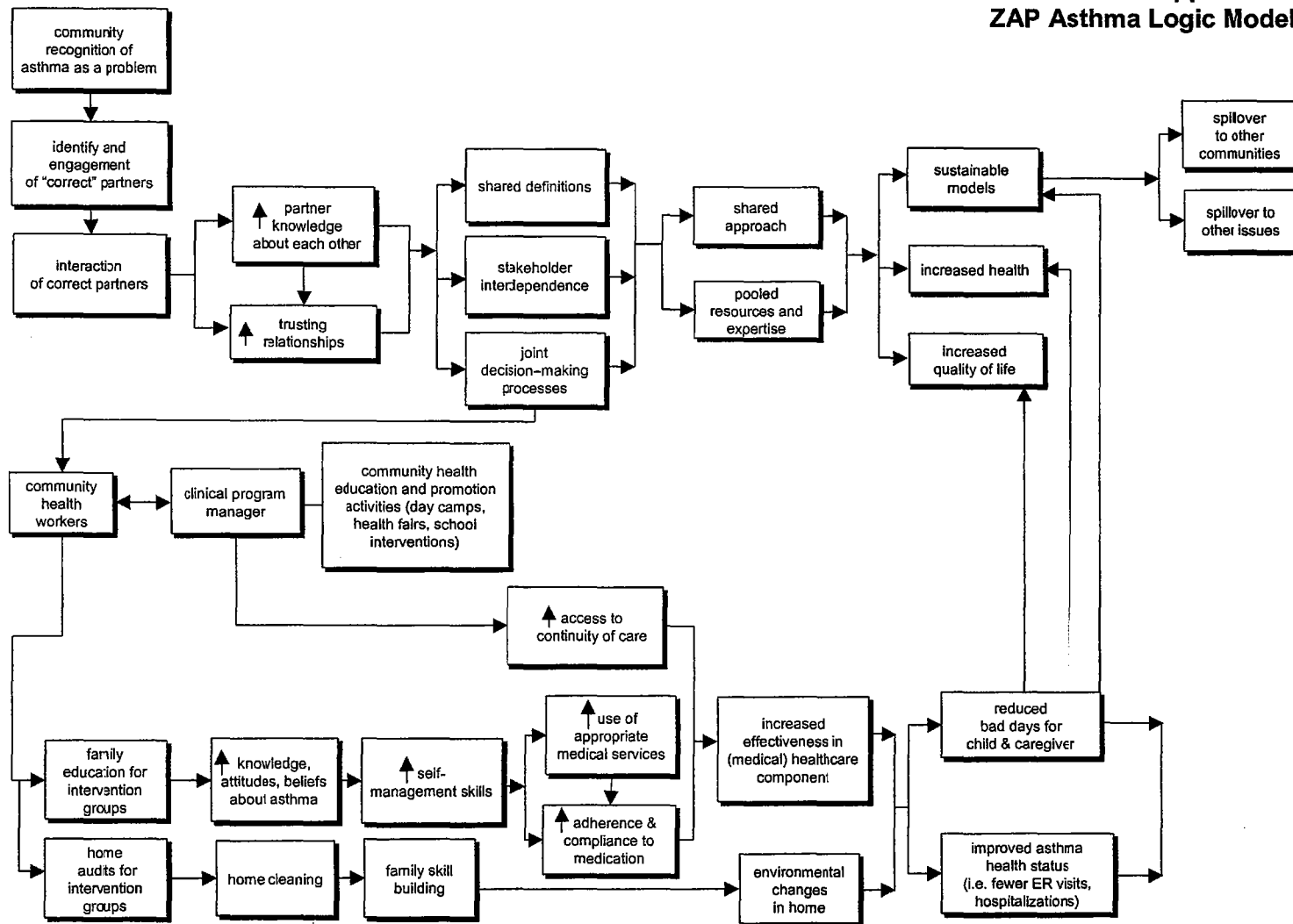
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1. What is your role in the consortium?
2. How would you describe the purpose of Zap Asthma?
3. What do you think the evaluation should focus on?
4. Are there fissures/tensions/factions within the group? If so, can you briefly discuss them?
5. What do you think the evaluation will show at this point in the life of the project?
6. What is unique about the approach that needs to be captured?
7. Who else should we talk to?

**Appendix B**  
**ZAP Asthma Logic Model**

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**Appendix B**  
**ZAP Asthma Logic Model**



**Appendix C**

**Interview Instrument and Interviews**

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**Interview Instrument and Respondents: Followup Interviews**

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**Interview Introduction**

**Respondent:** \_\_\_\_\_

**Date:** \_\_\_\_\_

- ❑ Doing this for CDC. Intent is to assess where ZAP has been and where it is going. Not strictly an outcome evaluation—which is being undertaken as part of the science protocol. Rather looking at important issues of process—in particular, how has the partnership evolved and how have some of the innovations ZAP brought to bear been implemented.
- ❑ Did an open-ended effort at the start of this assessment project. This is a slightly more quantitative approach in that a portion of the interview will consist of short answer and scale items.
- ❑ ZAP and CDC will use the data to assess current status, to compare with earlier data collected to determine where progress has been made and to use in the future to monitor progress.
- ❑ Doing many of these. Your responses will be aggregated with others. Your responses will not be identified by name.
- ❑ Feel free to make any comments you wish, even as we go through the scale items. I'll also be probing your responses with some open-ended questions later in the interview.

Attribute	General 1 – 5	Recent +, 0, -	Comments
<p><b>Focus:</b> Inter-organizational/community process including public/private/community collaboration, community engagement and empowerment, systems improvement, and capacity building at the community level.</p>			
<p><b>Study Question:</b> (How) did disparate organizational “players” become an active inter-organizational collaborative? (How) did the inter-organizational collaborative engage and interact with the community in an effective way? (How) did the collaborative approach lead to community empowerment? (How) did the collaborative approach lead to system improvement and capacity building at the community level?</p>			
Background on respondent			
Who representing			
Own role played in ZAP partnership			
Level of activity/involvement			
What they see as main goals of ZAP as an initiative			
<p>Himmelman continuum: For each item, ask 1 – 5 for general ZAP performance over life of project, and +/0/- for whether recent performance has gotten better, worse, or stayed the same. Feel free to say DK. Feel free to make comments.</p>			
<p><b>To what degree have ZAP partners had a shared:</b></p>			
<input type="checkbox"/> Shared or common vision			
<input type="checkbox"/> Shared or common definition of the problem			
<input type="checkbox"/> Shared or common approach to the problem			
<input type="checkbox"/> Sense of “joint ownership,” that is, a sense that they are an integral part of ZAP			

Attribute	General 1 – 5	Recent +, 0, -	Comments
<input type="checkbox"/> Appropriate distribution or power among the partners regarding ZAP POLICY (probe for too little or too much power if answer No).			
<input type="checkbox"/> Appropriate distribution or power among the partners regarding ZAP OPERATIONS (probe for too little or too much power if answer No).			
<input type="checkbox"/> Has ZAP resulted in coordinated service delivery activities			
<input type="checkbox"/> Has ZAP resulted in coordinated locations and hours by service providers			
<b>Here are some characteristics of an organization’s decision making. For each one, tell me the degree to which ZAP decision making, in general, has exhibited this characteristic on a 1 – 5 scale. And, again, whether in the last 6 months, things have gotten worse, better, or stayed the same.</b>			
<input type="checkbox"/> POLICY Decisions are made in a timely fashion			
<input type="checkbox"/> POLICY Decision-making process is inclusive, that is, involves all parties who should have some say in the decision			
<input type="checkbox"/> POLICY Decisions “stick,” that is, once made, do not need to be revised			



Attribute	General 1 – 5	Recent +, 0, -	Comments
<input type="checkbox"/> OPERATIONAL Decisions are made in a timely fashion			
<input type="checkbox"/> OPERATIONAL Decision-making process is inclusive, that is, involves all parties who should have some say in the decision			
<input type="checkbox"/> OPERATIONAL Decisions “stick,” that is, once made, do not need to be revised			
<input type="checkbox"/> ZAP has a governance structure that includes accountability for decisions			
<input type="checkbox"/> Board plays appropriate role in operational decisions (probe for too much or too little if low score)			
<input type="checkbox"/> Front-line staff like the CHWs are involved appropriately in decision making about OPERATIONS			
<input type="checkbox"/> Front-line staff like the CHWs are involved appropriately in decision making about POLICY			

Attribute	General 1 – 5	Recent +, 0, -	Comments
<input type="checkbox"/> Effective communication mechanisms			
<input type="checkbox"/> Problem identification and resolution mechanisms			
<b>To what degree have ZAP partners:</b>			
<input type="checkbox"/> committed resources to the project			
<input type="checkbox"/> met their commitments on resources			
<input type="checkbox"/> actively participated			
<input type="checkbox"/> been in conflict with each other that was unproductive			
<input type="checkbox"/> understood other partners' roles			
<b>Here are some questions about ZAP and the community. In particular, about ZAP's level of visibility and degree to which it has involved key segments of the community . . .</b>			
<input type="checkbox"/> HOW VISIBLE (I.E., HOW MUCH IS KNOWN ABOUT ZAP BY): <input type="checkbox"/> average community resident/person on the street			
<input type="checkbox"/> community leadership/power structure			
<input type="checkbox"/> community institutions (i.e., churches, merchants, organizations . . .)			

Attribute	General 1 – 5	Recent +, 0, -	Comments
<input type="checkbox"/> HOW MUCH HAS ZAP INVOLVED <input type="checkbox"/> average community resident/person on the street			
<input type="checkbox"/> community leadership/power structure (probe for which if say different or depends)			
<input type="checkbox"/> community institutions (i.e., churches, merchants, organizations . . . ) Probe for which ones if say different or depends.			
<input type="checkbox"/> engaged residents of the community			
<input type="checkbox"/> engaged institutions in the community (probe for which ones if different or “depends”)			
<input type="checkbox"/> involved the affected families in decision making about care of their child			
<input type="checkbox"/> helped families make good decisions about their health as it relates to asthma			
<input type="checkbox"/> helped families make good decisions about their health in general			

Attribute	General 1 – 5	Recent +, 0, -	Comments
<input type="checkbox"/> made the average community resident better able to approach and deal with institutions like government and health systems			
<input type="checkbox"/> made community leadership/power structure better able to deal with institutions like government and health systems.			
<input type="checkbox"/> built capacity of the community leadership/power structure to do an initiative like ZAP on its own in the future			
<b>Here are some other system impacts. Tell me if ZAP has led to these impacts on a 1 – 5 scale, and if in the last 6 months, things have gotten better, worse, or stayed the same.</b>			
<input type="checkbox"/> resulted in health system improvement for residents of the ZAP community, that is, a system that is more responsive to their needs			
<input type="checkbox"/> built capacity of service providers in the ZAP area to deal with pediatric asthma			

Attribute	General 1 – 5	Recent +, 0, -	Comments
<input type="checkbox"/> built capacity of service providers (like MDs and hospitals) and payors (managed care plans and insurance companies) to deal with the community			
<input type="checkbox"/> stimulate economic revival or development			

## Open-Ended Items

Item	Comments
<b>ZAP hopes to make an impact on systems and service delivery. From where you sit, could you tell me a little bit about how/if ZAP is effectively addressing:</b>	
<input type="checkbox"/> New patterns of service delivery	
<input type="checkbox"/> How it deals with challenges and barriers to implementing ZAP (i.e., the recruitment of families issue)	
<b>We asked you before to characterize the partnership on some dimensions. Let me probe a little bit on some of these areas. Can you tell me how the collaborative accomplished/ achieved (or if they gave low marks, how the partnership fell short or ran aground on):</b>	
<input type="checkbox"/> Shared definitions, visions, and values	
<input type="checkbox"/> Effective decision-making structures	
<input type="checkbox"/> Problem identification and resolution	
<input type="checkbox"/> Integration and interdependence of all members	
<b>For ZAP to be (more) successful in the future, what are some additional:</b>	
<input type="checkbox"/> In general	
<input type="checkbox"/> Skills needed	
<input type="checkbox"/> Resources needed	
<input type="checkbox"/> Stakeholders needed	
<b>Here are some potential “legacies” of ZAP. For each one, tell me the degree to which you think ZAP has achieved it and a little bit about how.</b>	
<input type="checkbox"/> What has your organization learned as a result of participation in ZAP? What is the legacy of your participation?	
<input type="checkbox"/> What screening criteria would your organization use next time in deciding how and whether to get involved:	
<input type="checkbox"/> How about other partner organization?	
<input type="checkbox"/> How about larger institutions and systems like the health department or the health care system? What have they learned from ZAP if they participated?	
<input type="checkbox"/> What could they learn from the ZAP experience (even if they were not part of this experience)?	

<b>Sustainability of ZAP components: ZAP created an infrastructure that may or may not have life/utility beyond the duration of the project. We'd like your opinion about other uses to which components of ZAP might be put.</b>	
<input type="checkbox"/> How about the collaborative partnership and the 501(c)(3)? What next for them? Is there life after ZAP?	
<input type="checkbox"/> (How) can the CHW function be sustained beyond the ZAP Asthma initiative?	
<input type="checkbox"/> What were the strengths of community health worker approach from your perspective? <input type="checkbox"/> Where else might this approach be used?	
<input type="checkbox"/> What were the weaknesses of community health worker approach? What would need to be addressed to make the approach transferable?	

**Appendix D**

**Moderator's Guide:  
Family Focus Groups**

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**Moderator’s Guide: Family Focus Groups**

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**I. INTRODUCTORY WARM-UP**

Thanks for taking the time to be here. *(Introduce self and note taker)*

I want to take a few minutes to tell you what to expect from our discussion tonight and to give everyone the chance to introduce themselves.

As you recall from the materials you received, this research is sponsored by ZAP Asthma, a community-based program designed to help improve the lives of children with asthma. We are not here to push any particular agenda or points, but rather to hear your frank and honest opinions about your experiences with ZAP Asthma. There are no right or wrong answers, no current habits or behaviors to be ashamed of. We all have our own likes and dislikes and our own thoughts and feelings about asthma. We just want to identify and understand the important issues that you are facing when you make decisions about your child’s health and medical treatments, particularly as it relates to asthma.

I want to remind everyone that the discussion here is confidential. We will not report your comments by name, and we ask that you respect one another’s privacy in the same way. We don't expect you tell us anything that you would be uncomfortable sharing with the group. But we do hope that you will be honest with your responses to the questions I ask.

Before we begin, I am handing out the informed consent form. I will go over it with you and then ask you to sign it. We want to make sure that you understand that your participation in this study is completely voluntary. That means you can leave at any time.

**REVIEW AND COLLECT INFORMED CONSENT FORM**

I'm going to ask a series of questions, but mainly we want to hear from you. My role is to guide the discussion. Sometimes we may really get going on one question, and I'll have to move you on to the next question so that we cover everything. Please don't take that personally! We just need to hear from you about several topics. We want to hear from all of you, so don't hesitate to speak up.

I'd also like to remind you that we will be audio-taping the conversation so that we can have an accurate record of what was said. No one will be identified or reported by name. Please try to speak clearly and one at a time, if possible.

Do you have any questions before we get started?

Let’s go around the room and introduce ourselves. My first name is \_\_\_\_\_. I’m from \_\_\_\_\_. The thing I like most about myself is \_\_\_\_\_ or \_\_\_\_\_. My favorite way to spend time is \_\_\_\_\_.

## I. Knowledge of Asthma, Its Triggers, and Chronic Nature

[Interested in their level of knowledge about asthma, the triggers and/or its chronic nature; their lack of awareness or understanding about this may influence their willingness to continue]

- A. What is asthma?
- B. Why do you think your child gets sick? What causes him/her to have an asthma attack?
- C. How serious an illness do you think asthma is?  
*Probe: Is asthma something that “goes away,” like a cold, after a child has been treated?*
- D. What are some things your or your child can do to prevent him/her from getting sick or having an asthma attack?

## III. Knowledge and Understanding about ZAP Asthma

- A. How did you hear about ZAP Asthma?  
*Probe: friend, emergency room, doctor, clinic, nurse*
- B. Who explained the program to you?
- C. Do you think the program was explained well? Why or why not? ( Do you think you had enough information to make a good decision about joining ZAP Asthma?)
- D. Why did you decide to participate in ZAP Asthma?  
*Probe: What did you think were the benefits of ZAP Asthma?*
- E. What attracted you most to ZAP Asthma?

## IV. Relationship with CHWs

- A. When did you first meet or talk to your community health worker?
- B. How well did you know your community health worker?
- C. Did you feel like you could turn to your community worker when you had a question about your child’s asthma? Why or why not?  
*Probe: Was it easy to reach them when you had a question or problem?  
Were they able to answer your questions?  
Did they make you feel comfortable?*
- D. Can you describe some ways that your community health worker was able to help you with your child’s asthma?

E. Did you trust the information you received from the CHWS?

## **V. Reasons for Discontinuing**

A. At what point did you decide not to continue participating in ZAP Asthma? Why?

*Probe: lack of transportation?  
lack of childcare?  
inflexible clinic hours?  
too time consuming?*

B. What are some other reasons you decided not to continue?

C. What did you like least about ZAP Asthma? Did this affect your decision to not continue?

D. Can you think of specific things that could have been done to make it easier for you to participate in ZAP Asthma?

E. Can you think of any incentives you were offered or received for your participation in ZAP Asthma? If so, how important were they in your decision to participate?

F. Can you suggest other types of incentives that may have been more effective?

G. What were some of the positive things about being in ZAP Asthma?

## **Conclusion**

We want to thank you very much for taking time to participate in this discussion. We appreciate and value your input.

## **Appendix E**

### **Moderator's Guide: Provider Discussion Groups**

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## Appendix E

# Moderator's Guide: Provider Discussion Groups

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### **Background and Warm-Up**

Thanks for taking the time to be here. (*Introduce self and note taker*)

I want to take a few minutes to tell you what to expect from our discussion tonight and to give everyone the chance to introduce themselves. As you recall from the materials you received, this research is sponsored by ZAP Asthma, a community-based program designed to help improve the lives of children with asthma. We are not here to push any particular agenda or points, but rather to hear your frank and honest opinions about ZAP Asthma and its utility to your work. There are no right or wrong answers, no current habits or behaviors to be ashamed of. We all have our own likes and dislikes and our own thoughts and feelings about asthma. We just want to identify and understand the important issues that you are facing when you make decisions about dealing with the health of communities like the AEZ.

### **Video and Presentation**

I'm going to open with a short video that describes ZAP Asthma. [Show video . . .]

[At conclusion of video. . . ] To help frame the discussion about ZAP Asthma, let me give you a framework for thinking about it that may be helpful. We think of ZAP Asthma as a set of concentric circles:

- Center circle: The science/research protocol
- Second circle: Education and outreach oriented to the families and to the larger community
- Outer circle: Systems interconnections and systems change. Helping all partners better learn how institutions, communities, and families can work in partnership

The Community Health Workers (CHWs) are the link among the circles in that they deliver the intervention to the families, act as a link between the families and the system, bring resources from the system to the families, and, as importantly, bring the reality of the lives of families and the community to protocols and to institutional partners.

Do you have any questions about that framework? We'd like you to think about the utility of all those layers of ZAP Asthma to the work you do.

1. What about the model sounds most like it would add value to your current efforts?  
*Probe by rings of the circle and identify aspects in each ring if possible.*
2. How about the CHW model? (How) might that work for you?
3. To what other conditions that you deal with might the ZAP Asthma model be applied?  
*Probe for specific conditions.*
4. [Once the list is complete . . . ] Let's think about what these conditions might have in common so we might profile the "ideal" condition for applying the ZAP Asthma model.
5. When you think about applying the ZAP Asthma model, are you thinking mainly about the aspects related to community participatory planning and collaboration or the CHW approach or both?
6. What are the longer-term or broader ZAP impacts for your organization? (How) might the fact that ZAP Asthma has "been there" help your organization in working with these communities?

## **Conclusion**

We want to thank you very much for taking time to participate in this discussion. We appreciate and value your input.