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Stirring up the Mud: Using a Community-Based Participatory Approach to Address Health Disparities through a Faith-Based Initiative

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Abstract

This case study provides a mid-course assessment of the Bronx Health REACH faith-based initiative four years into its implementation. The study uses qualitative methods to identify lessons learned and to reflect on the benefits and challenges of using a community-based participatory approach for the development and evaluation of a faith-based program designed to address health disparities. Key findings concern the role of pastoral leadership, the importance of providing a religious context for health promotion and health equality messages, the challenges of creating a bilingual/bi-cultural program, and the need to provide management support to the lay program coordinators. The study also identifies lessons learned about community-based evaluation and the importance of addressing community concern about the balance between evaluation and program. Finally, the study identifies the challenges that lie ahead, including issues of program institution-alization and sustainability.

Keywords

Health disparities; race/ethnicity; community-based participatory research; faith-based initiatives

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As part of the Racial and Ethnic Approaches to Community Health (REACH) program, the Centers for Disease Control and Prevention funded a coalition in the southwest Bronx, led by the Institute for Family Health, to reduce morbidity and mortality resulting from diabetes and related cardiovascular disease. The southwest Bronx, [*] where the Bronx Health REACH Coalition is located, is more than 95% Black and Latino. There are roughly 280,000 residents in the REACH target area, more than 41% of whom are living below the poverty level.[1] Sixteen percent of the residents of this community have been diagnosed with diabetes, compared with 9% in New York City, and the age-adjusted diabetes hospitalizations rates are 914 per 100,000, compared with a City rate of 355 per 100,000.[2]

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[*]The program area includes ZIP codes 10452, 10453, 10456, and 10457.

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As part of a multifaceted approach to addressing this problem, the Coalition, which formed in 1999, created a strong faith-based initiative. By early 2007, this initiative was being implemented in 17 churches of various denominations, including Baptist, Episcopalian, Evangelical, Seventh Day Adventist, and Catholic. The congregations range in size from 20 to 1,000 members, totaling roughly 5,000 individuals. The faith-based outreach initiative has two goals: (1) to use the capacity and resources of local faith-based institutions to change the knowledge, attitudes, and behavior of community members concerning health promotion, disease self-management, and navigation of the health care system; and (2) to mobilize clergy and church members to seek changes in law, regulation, and policy to promote equal access to care.

In each church, the senior pastor commits to sharing information from the pulpit about health promotion and racial disparities in health. The pastors also agree to select a health coordinator from the congregation to be trained by REACH staff to lead a variety of activities including screenings, nutrition workshops, fitness classes, and weight loss support groups. The Coalition supplies most of the printed materials and other resources required to implement activities, and provides $3,000 per year to each church for expenses related to the project.

Many public health and health education initiatives have been implemented through collaborations with faith-based institutions.[3-12] In many communities, faith-based institutions are important social anchors, and many have organizational structures and communications systems that can be used to implement health programs or transmit health messages.[3] While the relationship between health and faith is known to be strong in many communities,[13] little is known about appropriate models for developing faith-based health initiatives.[14,15]

Early on in the Bronx Health REACH faith-based initiative, the Center for Health and Public Service Research (CHPSR) of New York University studied the program's implementation, using a community-based participatory approach. Our goal was to understand how the Bronx Health REACH churches had been mobilized and to identify the factors that facilitated the work of the faith-based initiative, as well as the barriers that were encountered and the lessons learned.[16]

In keeping with its commitment to the ongoing assessment, improvement, and expansion of its activities, the Coalition successfully applied for funding from the National Institutes of Health's (NIH) National Center on Minority Health and Health Disparities to develop a program toolkit and to pilot replication of the faith-based initiative and evaluate its impact in an additional group of churches.

We recognize that it is unusual, particularly in community-based work, to have the resources and time to reflect on, refine, and expand a program mid-stream. In this paper, we first describe how we used a community-based participatory approach to undertake this midcourse assessment. We then discuss the key insights gained through this process and how these findings are being used to shape the new initiative and improve the existing program. The paper then describes our community-based approach to conducting surveys in the program and control churches. We conclude with a discussion of challenges and plans for the future.

Laying out the ground rules. In response to the NIH requirement that the applicant form a community advisory group, the Coalition leadership recruited a community research committee (CRC) from within its membership. Because the Coalition had been largely focused on program development and implementation, a research grant of this kind required a somewhat different orientation. The first task that the CRC identified was to articulate the

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value and role of research. The group debated and discussed the questions, “Why do research and evaluation? Why not just concentrate on program development and implementation?” and concluded:

> We want to know whether our interventions are effective in changing the knowledge, attitudes, beliefs, and behaviors of program participants, and we want to understand how to strengthen our efforts. We need evidence in order to disseminate our findings to different audiences in an effective and persuasive way, and to obtain additional funding to continue our work. Done right, research and evaluation will help guide and improve our work, and help sustain it.

This question has arisen on subsequent occasions, particularly as the Coalition has applied for other research grants with similar expectations in terms of scientific rigor. Because continuation of program funding is so essential and so difficult to come by, there is an understandable desire among Coalition members to use any available money to support program activity. A continuing ambivalence about giving priority to a research agenda is reflected in the name of the community committee, which sometimes refers to itself as the Community *Research* Committee, and other times, the Community *Resource* Committee.

Another early task for the committee was to articulate the principles that underlie a community-based participatory approach (CBPA). Many of the methods and values that the CRC agreed upon can be found in the literature,[17-20] and are illustrated below. But a unique contribution that emerged from these discussions was the conviction that CBPA requires a long-term commitment from all participants to the goals of the effort, not just to a funded or time-limited project. The CRC concluded, “We are engaged in this effort because we care about and want to help improve the health and well being of this community: We are in this for the long haul. This is not a project; it is a commitment.”

Reflecting on the program’s strengths and weaknesses

In the first year of the NIH grant, the CRC held five large focus groups (two of which were in Spanish) with a total of 89 church members and conducted interviews with the 13 faith-based coordinators and pastor leaders, and with six pastors and coordinators of churches that are no longer participating in the program. As all of the Coalition’s evaluation and planning does,[21-24] this work took a community-based participatory approach. Two members of the CRC led the focus groups, with the assistance of CHPSR researchers and Bronx Health REACH program staff. All of the interview and focus group protocols were developed in collaboration with the CRC. All findings were presented to the CRC as a group, and their implications for program development and improvement were discussed at length.

The interviews and focus groups centered on issues relevant to program effectiveness and replication. We ended each discussion by asking participants which program elements they would keep and which they would eliminate or change, if they were advising another church about program implementation.

Several members of the CRC strongly advocated for a special emphasis on understanding the extent to which the Coalition’s messages about health equality have been incorporated into the program, and the resonance of those messages within the congregations. (The statement quoted at the beginning of this report was part of an email exchange that followed a meeting on this topic.) Based upon our earlier work on this issue, members of the CRC agreed that “people would be reticent to express their concerns … about an issue potentially touching on race, unless they were in a setting in which they were given ‘permission’ to do so.”[21] Many members of the CRC had strong feelings about how race and racism are perceived and discussed in our society, so this topic presented a challenge for the focus

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group facilitators: how to open the door to a discussion of health disparities and discrimination in a way that encourages participation and allows people to express a range of views, but remains unbiased and dispassionate.

Several themes that emerged in our earlier implementation evaluation re-emerged in this look-back at the program.[16] For example, we heard again about the central role of the pastor,[3,25-27] and about the importance of connecting health messages to spiritual messages.[28-30] We also observed great variation among the churches in their responses to the health equality message. And we learned some concrete lessons about program management. These findings are summarized below, together with a description of the programmatic changes made by the faith-based initiative in response to these insights.

Role of the pastor

In every focus group and interview, participants confirmed that pastoral leadership is essential. But many, including several pastors, also observed that information about diabetes prevention and management and the concept of health disparities is new to most church leaders, and pastors need education and training. Pastors and the faith-based coordinators suggested that pastors would be most receptive to guidance from other pastors, who could provide the scriptural context and references for this information.

In response to these findings, the CRC asked two of the pastors to take the lead in developing materials specifically written for other pastors that address the religious underpinnings and context for much of the education and outreach. (These are described below.)

Content of the health message

There was a strong consensus among focus group participants and interviewees that linking health messages to religious tenets is critically important. As one congregant said, "Use the scriptures that the body is the temple of the living God and that you have to take care of your temple." An assistant pastor at one church explained in detail:

> It really was Bronx Health REACH that inspired me to preach that sermon because I wanted my brothers and sisters … to embrace their good health from a spiritual perspective … that this body houses the Holy Spirit, that that makes it a very, very special and sacred chapel that we are to revere in the same way that we want to take care of this building. You know, as soon as something is wrong, we're repairing, we're fixing, we're painting, we're mopping, we're sprucing up, we're hanging curtains. And yet … it has been okay for us to fill our bodies with garbage. But we wouldn't take a bag of garbage and dump it on the floor of our church.

In response to these discussions, the staff, assisted by a church deacon, made sure to include references to scripture in all program materials.

In addition, the CRC recognized that religious beliefs can play a strong role in how congregants view illness and influence when and from whom they seek care. Dr. Robert Foley, the Pastor of Cosmopolitan Church and pastoral leader of the faith-based initiative, was asked by the CRC to develop materials that would shed light on these issues and might serve as a resource for other pastors. In the treatise he wrote in response to this request, *A Theology of Sickness*, Dr. Foley notes that many church members feel a sense of inevitability or "surrender" in the face of illness. He quotes frequently heard sentiments:

> There is nothing I can do because God is in control;
>
> This is my cross, and I've just got to bear it;

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> Well, it's the Lord's will, and God's will must be done.

In the treatise, Dr. Foley acknowledges that these thoughts can provide a sense of comfort and peace, but he cautions they may also "preclud[e] that person from seeking and utilizing the full range of the services available to them." He offers the counter-argument that although suffering can "serve a redemptive purpose," "Faith does not demand the abandonment of common sense, or a rejection of aid and assistance apart from God." Dr. Foley presented his paper at the Pastors' Breakfast Conference, and it was later included in the toolkit for the program.

Content of health equality message

Although in every focus group participants told stories about feeling discriminated against and mistreated by the health care system, in only two churches was education about health disparities an integral part of the initiative. In those two churches congregants were extremely well informed, citing very specific examples, such as "the disparity in life expectancy between the Caucasian race and the African American race." One person described the information they had received through REACH: "We received statistical information. Mathematics showing percentages of persons in the Bronx with diabetes, with asthma … . We received statistics on who has health coverage and who doesn't."

In both of these churches, the pastors have linked health behavior and health equality and placed both messages in a spiritual context. One church member articulated the connection between caring for oneself—health behavior—and expecting good care from others—health equality: "You are a child of God and you believe that God loves you. This raises the self esteem and raises your self consciousness to a level where you want to be your best and you want the best for yourself."

Although at the time of the focus groups, health disparities and discrimination had not been discussed in the other churches, focus group participants and the faith-based coordinators in all of the churches expressed the view that the church was a good setting in which to have these conversations: "There is a sense of empowerment," "You feel so free you can ask anything and you don't feel stupid." Several people noted that in such a discussion it is important to raise people's expectations: "Disparities have been there from the beginning … people expect to be treated as second-class citizens." Others suggested that the term "health disparities" is confusing and that the program needs to find a way to discuss these issues in a language that people can understand. Several of the faith-based coordinators suggested that the health equality message needs to be placed in a spiritual framework in all of the churches.

In response to these insights, a diabetes educator who is a member of the CRC (RR), drafted a guide entitled Health Disparities Commonly Experienced by People of Color. This document is intended to help people identify systemic and individual forms of discrimination and to raise their expectations.

In addition, the CRC asked a Coalition member, Reverend Dr. J. Albert Bush, Pastor of Walker Memorial Baptist Church, to develop a companion piece to *A Theology of Sickness* that would provide a spiritual context for the argument for health equality. In his treatise *A Theology of Equality*, Dr. Bush cites scriptural evidence of "God's personal interest, involvement and active participation in the eradication of political, social and economic injustice and inequality," and he challenges the church to act prophetically in "serving as the mouth-piece of God" by confronting "contemporary injustices and inequalities of all kinds." Dr. Bush presented his treatise at the Pastors' Breakfast Conference, and it too was included in the toolkit for the program.

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Recruiting and engaging predominantly Hispanic/Latino churches

From the initiative's early years, pastors commented on how unusual and impressive it was that the Coalition was able to cross denominational boundaries. But the churches, varied as they were by denomination and size, were largely African American and Caribbean. In interviews with lay and pastoral leaders from predominantly Hispanic/Latino churches, we explored possible barriers to participation: Does the church play a different role in those communities? Is the program viewed as being by and for African Americans? Is there a way to connect with Latin American traditions of Liberation Theology to complement the emphasis on civil rights? These questions will be explored in greater detail in the next phase of the program, but we did learn that language was a much bigger barrier than we had realized. For example, at one large church, no one but the coordinator felt comfortable attending an English language meeting. When he fell ill for an extended period of time, there was no one else who could take his place. As a result, during that time, the church disappeared from the program.

In hiring a new project manager, the Coalition gave priority to finding someone who was fully fluent in Spanish. Even in the new project manager's (CD) first visit to a coordinators' meeting (before he was hired), the dynamic in the room changed and those whose primary language was Spanish played a much more active role. Once hired, the project manager was able to assess the program's bilingual status. He found that only 50% of the program literature had been translated into Spanish, and that the materials that had been translated were inconsistent (even the name of the program varied) and often incorrect. In addition, he found that scriptural passages had been translated word-by-word from the English language Bible, rather than using an accepted Spanish Bible text.

Since then, the project manager has systematically addressed the language issues. All REACH materials are in the process of being translated or, in the case of a video, subtitled, and prayers and other messages originally in Spanish (not lifted and translated word-for-word from English) have been incorporated into the program toolkit. The new policy for the program is that all new materials are translated as they are introduced, and all speakers are told be bring materials in both Spanish and English.

Supporting the coordinators

In our focus group with the faith-based coordinators, there was a strong consensus that the program should train the coordinators for the administrative, clerical, and management aspects of their roles. Several cited the challenges of planning ahead and managing time: "If you get something to pastor at last minute, she may tell you, 'I don't accept announcements on Sunday mornings.'" Others mentioned the nitty-gritty tasks of managing the clerical work and reporting. Many also talked about the skills needed to engage the pastoral leadership, such as "how to keep your pastor informed through memos, agendas, and reports." Others talked about the management task of recruiting, inspiring, and managing volunteers "to help you so you don't burn yourself out."

Program staff confirmed that the lack of project management experience for many of the coordinators had made program implementation, data collection, and monitoring more challenging. Working with a consultant recommended by CHPSR, the staff developed a management training program to help the coordinators increase their organizational and time-management skills, leadership capacity, and communications skills. The workshop also gave the coordinators the opportunity to provide feedback to program staff. As a result, the monthly data collection reports were simplified and clarified.

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Using a community-based participatory approach to surveying in the churches

The survey component of the evaluation used a quasi-experimental design with a comparison group, taking advantage of the fact that the Coalition was rolling out the pilot program over a two-year period. The REACH staff identified 11 churches that were interested in implementing the pilot program. All 11 churches participated in the baseline survey and all were surveyed one year later. (Data are currently being analyzed.) Six of the churches were selected to implement the program immediately and the remaining five served as the control group, with their participation in the program delayed for one year. In this way, the evaluation design controlled for possible volunteer bias since churches in both program and comparison groups demonstrated interest in participating in the program. The control churches received $500 after completing each survey.

The survey also used a community-based participatory approach. The CRC identified the domains for the survey instrument and vetted the language of proposed questions. This meant that standardized questions were sometimes rejected or revised. For example, early on, the Coalition members objected to any of the standardized checkbox methods for asking about race and ethnicity. Given that the survey numbers were relatively small, we opted for a simple open-ended question: "What is your race and/ or ethnicity?" leaving a blank line. In a different vein, members of the CRC found the language of the standard weight question ("About how much do you weigh without your shoes on?") to be absurd and even a bit disrespectful. They opted instead for a simpler format, without the shoeless caveat ("About how much do you weigh?").

The fielding of the survey initially proved more difficult than we had anticipated. In several churches, congregants had distributed the blank surveys before staff arrived so we were unable to keep track of the response rate. In one church, a well-meaning coordinator took a large stack of surveys and, we later learned, was distributing them to people not in attendance. Another church thought it would be useful to administer the survey in the evening when the health ministry was sponsoring a speaker on diabetes. (Since those in attendance would, by definition, be those most interested in diabetes, we returned at the time of the regular Sunday service.) Finally, in one church, a Coalition member who was assisting the surveyors announced the survey to the congregation by giving an articulate and passionate sermon about health disparities, thereby skewing the results to questions such as "Have you ever heard of the term *racial and ethnic disparities in health*? Do you know what the term *racial and ethnic disparities in health* means?"

As the CRC reflected on these challenges, we realized that we had not done the groundwork to ensure that there was a shared understanding with church leadership about the purpose and methodology of the survey. As one CRC member (JD) put it, "People need to know what you mean by 'help'!" In our second round of surveys, staff worked closely with the faith-based coordinators and liaisons to explain the process. We also brought the survey instruments with us (rather than sending them ahead of time), and had teams of students helping to distribute and collect the forms and answer questions.

The baseline survey results were shared with the pastors and discussed by the CRC, and several changes were made to the follow-up survey. Most significantly, we added an open-ended question about health disparities: "What does the term *racial and ethnic disparities in health* mean to you?" The purpose of this question was to assess whether people did, indeed, understand the term and, of equal importance, to see what words they used to describe the problem. We thought that the vocabulary used by respondents might provide some guidance to program staff about what words resonate.

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Challenges and plans

There are many challenges to developing, implementing, and evaluating a program of this size, ambition, and complexity.

Defining "community."

Early on, even before the grant application was submitted, the CRC confronted the question, What does it mean to be *community-based*? Although the REACH staff and academic partners saw the CRC as the *community-based advisory board*, other Coalition members who served on the committee assumed that a separate group of community members would be convened. Many of the CRC members had worked for years in the southwest Bronx, but several no longer lived in the neighborhood and did not view themselves as representative of the community or truly community-based. It was acknowledged that the composition of the CRC would likely meet the NIH requirement. But, at the same time, it was agreed that it was important to reach out to community residents, several of whom subsequently joined the CRC.

Continued engagement of community residents in a way that is meaningful and fair will likely remain a challenge for the Coalition, as it is for many other community-based efforts.[31] The members of the Coalition and of the CRC have varied relationships to the initiative: some are paid staff for member organizations, others are funded as part of a grant, and others, particularly many of the community residents, participate as volunteers. One of the goals of the CRC is to address this inequity through additional fundraising so that community members can be compensated for particular assignments or enhanced roles.

Ensuring that the evaluation is appropriate, equitable, and rigorous

As in other community-based research and evaluation, the tension between program needs and evaluation methodology continues and will likely rise to the fore when the requirements of the research design threaten to delay service delivery.[31] In the current phase of the program, because the staff lacked the capacity to implement the program in all of the churches simultaneously, the CRC did not have to confront this issue. But as interest in the program has increased and staff capacity has grown, in the next phase, the question of when and what to implement in the next group of control churches will likely become more pressing. In anticipation of this issue, the CRC has begun to explore appropriate and equitable ways to structure future evaluations (for example, by implementing different programs simultaneously in the program and control churches).

In addition, many of the hoped-for program outcomes (significant changes in health behaviors) will take more than one year to achieve. The CRC is in the process of developing interim measures that are linked to program theory to ensure that there is "a strong relationship between what is studied and how it is studied."[32]

Investing the time

Community engagement takes time—to build relationships, develop trust, and encourage meaningful participation.[33] This can be difficult for all parties involved: for example, for residents who may not have flexibility from their employers, and for overscheduled pastors and physicians. In research-oriented projects, this investment of time can feel like a luxury or a distraction from the true work at hand. Finding a balance between full engagement and some degree of efficiency (and the need to meet grant deadlines) will likely remain a challenge.

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Creating a fully bi-lingual, bi-cultural program

Although the faith-based initiative has made great strides in recruiting predominantly Hispanic/Latino churches and more fully integrating them into the program, creating and sustaining a fully bilingual, bi-cultural program remains a challenge. Ensuring that all materials are accurately translated is a large undertaking, and more complex than it might appear on first blush. For example, in translating and adapting the curriculum for the church culinary initia-tive, the staff learned that while the word for *orange* in Mexican-Spanish is *naranja*, in Puerto Rican–Spanish it is *china*, which in Mexican-Spanish means a *Chinese woman*. In addition, a bi-cultural program means that the nutrition initiative must incorporate dietary preferences from different parts of the world, and that community leaders must be identified who can adapt and run programs, such as the newly modified exercise program *Fine, Fit, and Fabulous* (*Fuerte, en Forma y Fabulosa*).

Engaging pastor leadership and expanding the reach

Pastor engagement remains a lynch pin of the initiative—and an on-going challenge. The CRC decided not to form a pastors' council and instead to recruit and work with pastors individually, holding periodic pastors' breakfasts. But the committee plans to revisit this issue in the future since it recognizes the potential power of tapping into a larger leadership group and perhaps reaching out to existing city-wide, state-wide, and national organizations. Without that vehicle or other forums, it has been challenging to distribute the treatises *A Theology of Sickness* and *A Theology of Equality* for use by other pastors.

Addressing health equality

While health behaviors are widely addressed in the participating churches, the topic of health equality and health disparities has made less of an inroad. Materials have been developed to make this subject more accessible from a lay and pastoral perspective, but how to distribute those materials and create a forum for that discussion remains a challenge. The two churches that have addressed this subject are those in which pastoral leadership on this subject has been strong. The challenge of imbuing the call for health equality throughout the program is very much linked to the challenge of engaging the pastors.

Sustaining the program

Finally, as with any community initiative, sustainability of the program is a challenge.[22] Parts of the faith-based initiative have now been integrated into church structures and ministries. For example, several of the pastors have become spokespersons on the issue of health disparities in local and national associations of religious leaders, and, in one case, the community board of a hospital. Several of the pastors routinely incorporate health messages into their weekly sermons, and many of the churches include clippings and other health-related materials (some provided by the Coalition and some from other sources) in the weekly church bulletins.[16] Many of the churches have changed the food that is served at church events, and one church has re-engineered and re-equipped its kitchen and created a Wellness Center. More recently, several of the faith-based coordinators have tapped into expertise on nutrition, exercise, and disease management within their churches, and several of the churches have integrated the REACH program into the ongoing work of their health ministries.

Institutionalizing change in this way has been possible because of the duration and flexibility of the funding. The long-term funding for the REACH program, and the funders' support for the program participants' self-reflection, allowed the Coalition to consider issues of sustainability in its program development and implementation. But the challenge remains. Finding supplemental funding, even small amounts, will be key to maintaining changes in

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program operations. With its commitment to continuing the work and remaining in the community "for the long haul," the Coalition is also looking for ways to continue the initiative with fewer resources.

> When I was a child in the Dominican Republic, sometimes we had to go fetch water at the local brook when our main reservoir ran out. We learned from a very young age that while we could play with the water by making circles in it with a stick, we should not go too deep or the mud at the bottom would surface and the water would then be too spoiled to carry home.
>
> Health disparities remind me of the mud at the bottom of the brook. They are always there, most of the time invisible. Sometimes, it takes a stick to stir them up and make them surface. I believe that Bronx Health REACH can be that stick. If we want to eliminate health disparities, we need to go beneath the surface and make them visible.
>
> —June 9, 2006 edited email from Rosa Rosen,
>
> member of the Community Research Committee

Notes

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